Faculdade de Ciências Médicas

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THE INFLUENCE OF BURDEN OF CARE AND PERCEIVED STIGMA ON EXPRESSED EMOTIONS OF RELATIVES OF STABLE PERSONS WITH SCHIZOPHRENIA IN NIGERIAN SEMI-URBAN/URBAN SETTINGS

BY

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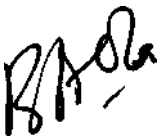
DECLARATION

This dissertation is submitted in partial fulfilment for the award of the International Masters in Mental Health Policy and Services Faculty of Medical Sciences, the New University of Lisbon.

It is hereby declared that this work is original unless otherwise acknowledged.

The work has not been presented in part or whole to any other College or Institution or Fellowship or Diploma, nor has it been submitted elsewhere for publication.



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Dr Bolanle Adeyemi OLA

CERTIFICATION

The study reported in this dissertation was done by Dr Bolanle Adeyemi OLA, under the supervision of Professor Julian Leff

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ABSTRACT

Schizophrenia's burden defines experience of family members and is associated with high level of distress. Courtesy stigma, a distress concept, worsens caregivers' burden of care and impacts on schizophrenia. Expressed emotion (EE), another family variable, impacts on schizophrenia. However, relationship between EE, burden of care and stigma has been little explored in western literature but not in sub-Saharan Africa particularly Nigeria. This study explored the impact of burden of care and courtesy stigma on EE among caregivers of persons with schizophrenia in urban and semi-urban settings in Nigeria.

Fifty caregivers each from semi-urban and urban areas completed a socio-demographic schedule, family questionnaire, burden interview schedule and perceived devaluation and discrimination scale.

The caregivers had a mean age of 42 (± 15.6) years. Majority were females (57%), married (49%), from Yoruba ethnic group (68%), monogamous family (73%) and Christians (82%). A higher proportion of the whole sample (53%) had tertiary education. Three out of ten were sole caregivers. Seventy three (73%) lived with the person they cared for. The average number of hours spent per week by a caregiver with a person with schizophrenia was 35 hours.

The urban sample had significantly higher proportion of carers with high global expressed emotion (72.7%) than the semi-urban sample (27.3%). The odds of a caregiver in an urban setting exhibiting high expressed emotion are 4.202 times higher than the odds of caregiver in a semi-urban setting. Additionally, there was significance difference

between the urban and semi-urban caregivers in discrimination dimension. High levels of subjective and objective burden were associated with high levels of critical comments.

In conclusion, this study is the first demonstration of urban-semi-urban difference in expressed emotion in an African country and its findings provide further support to hypothesized relationship between components of EE and burden of care.

Chapter One

1.0 Introduction

This chapter provides an introduction to the thesis topic. The purpose of the thesis is described. Background information about the factors relevant in this thesis about schizophrenia, such as burden of care, perceived stigma and expressed emotion, is summarized. The research questions and consequent objectives of the thesis are finally outlined.

Schizophrenia is a severe mental disorder which usually starts in adolescence or early adult life and often has a chronic disabling course. Even if schizophrenia is not a very frequent disease, it is among the most burdensome and costly illnesses worldwide (Rossler et al., 2005). It usually starts in young adulthood. Life expectancy is reduced by approximately 10 years, mostly as a consequence of suicide. Life expectancy in schizophrenia is also reduced by the side effects of antipsychotic medication, such as diabetes and weight gain, and by life style issues such as smoking and lack of exercise. Even if the course of the illness today is considered more favorable than it was originally described, it is still only a minority of those affected, who fully recover.

Schizophrenia was estimated to be the 10th leading cause of non-fatal burden in the world in 1990, accounting for 2.6% of total years lived with disability (YLD), around the same percentage as congenital malformations (Sartorius et al. 1986). Schizophrenia is listed as the 8th leading cause of disability-adjusted life years (DALY) worldwide in the age group 15-44 years (WHO, 2001). According to the Global Burden of Disease Study,

schizophrenia causes a high degree of disability, which accounts for 1.1% of the total DALYs and 2.8% of years lived with disability (YLD).

Schizophrenia has a significantly huge cost to the patient in terms of personal suffering, on the caregiver as a result of the shift of burden of care from hospital to families, and on society at large in terms of significant direct and indirect costs that include frequent hospitalizations and the need for long-term psychosocial and economic support, as well as life-time lost productivity (Awad and Voruganti, 2008). The direct costs of schizophrenia are large, ranging from 0.5% to as high as 3.5% of national healthcare expenditures and the productivity costs larger, with estimates ranging from equivalent to direct costs to up to five times higher than direct costs (Awad and Voruganti, 2008). According to these authors, despite affecting only up to 1% of the population, the financial burden of schizophrenia on patients, friends, family members, and the general healthcare system is substantial. In Low and Middle Income Countries (LAMIC), this burden compared with High Income Countries (HIC) is more and especially would be grave in rural areas where access to care is poor in sub Saharan Africa. In Nigeria, for instance, where 70% of the population live in the rural areas, one expects the burden to be more than in urban areas.

The burden of care on caregivers is more defined by its impacts and consequences on caregivers. Burden of care involves ideas such as shame, embarrassment, feelings of guilt and self-blame and as well emotional, psychological, physical and economic impact on the carers (Chen et al., 2005; Laidlaw et al., 2002; McDonnell et al., 2003; Milliken and Rodney 2003; Rudge and Morse 2004; Tsang et al., 2002; Tsang et al., 2003; Awad and Voruganti, 2008). Demands of care-giving include paying for psychiatric care, adopting a

supervisory role, dealing with stigma associated with mental illness and emotional distress, dealing with possible substance abuse problems and patient suicide attempts (McDonnell et al., 2003). Other burdens include guilt and increased stigma and isolation (Rudge and Morse 2004; Tsang et al., 2002; Tsang et al., 2003). Some caregivers report being discriminated against, avoiding social situations and not telling others about their family member's condition (Tsang et al., 2003). Some siblings have reported fears about the hereditary nature of schizophrenia and their potential to develop the condition (Stalberg et al., 2004). These studies were conducted in the western world and mainly in urban areas. Literature on burden of care with a specific focus on people with schizophrenia living in rural areas is scarce or non-existent especially in sub-Saharan Africa.

The impact of patient's symptoms on burden of care has been researched but there is no complete agreement on whether a specific cluster of psychotic symptoms has the most impact on a caregiver's burden of care (Awad and Voruganti, 2008). However, there is agreement that the severity of symptoms increases it.

A review of the literature reveals that the higher the perceived family burden of mental illness in carers, the higher the level of distress, suggesting that the perception of burden is a risk factor for higher levels of stress in carers (Wong et al., 2005). Hence the amount of stigma perceived by carers is related to the amount of stress borne by them. When there is higher level of stress, the impact on care-giving would be negative and subsequently, the impact on the course of the illness would be negative. It is therefore interesting to note that there is abundant literature on family interventions in

schizophrenia that has demonstrated the positive impact of various family interventions in improving family environment, reducing relapse and easing the burden of care.

A significant family variable that impacts on the course of schizophrenia is expressed emotion (EE). EE is a measure of emotional attitudes as expressed by a key relative (typically a parent, less frequently a spouse or sibling) to an interviewer during the one to one and half-hour Camberwell Family Interview (CFI; Vaughn and Leff 1976), usually administered during the patient's hospitalization. Various studies have reported that EE predicts outcome among patients with schizophrenia. These studies on EE have grown out of the work of Brown, Birley, and Wing (1972). These British researchers reported that certain family styles characterized by high EE influenced the course of schizophrenia. High EE, according to these authors, led to the increased probability of exacerbation of symptoms or relapse. Family interventions with a focus on EE have demonstrated positive impact on the course of schizophrenia (Bebbington and Kuipers, 1994; McCreadie, 2004). There is need for cross-cultural studies in sub-Saharan Africa to examine EE among families of persons with schizophrenia especially in the environment where most of the people live. This study examined EE in families of persons with schizophrenia living in rural areas compared with those in urban cities.

However, the use of hospitalised patients in most of these Western EE studies produced several potential confounds that led other researchers to question the implication that EE in the family causes the patient's subsequent clinical course. One major confound, that has been addressed in Western settings (Tarrier and Barrowclough, 1987), is that recruiting subjects at admission to hospital may bias the sample toward more frequent relapsers, who are likely to have a preponderance of positive, versus negative, symptoms

(Pogue-Geile and Harrow 1984). Another difficulty is that there is little evidence that EE at admission is a reliable indicator of EE during the follow-up period prior to any relapse (King and Dixon, 1999). This has however been addressed in Western literature too (Bebbington and Kuipers, 1994; McCreadie, 2004). This study examined EE in families of persons with schizophrenia who are outpatients.

Given that relatives experience significant stress as a consequence of the illness and that the problems and burdens of living with a schizophrenia sufferer are considerable (Creer and Wing 1974; Gibbons et al. 1984; Fadden et al. 1987; MacCreadie and Robertson 1987; Bland 1989), research into the problems of the relatives themselves is limited. The relationship between EE, burden of care and stigma has been little explored in western literature and has not been explored in sub-Saharan Africa particularly in Nigeria. This study therefore aimed to explore the impact of burden of care and perceived stigma on EE among geographically diverse relatives of outpatients with schizophrenia.

1.1 My research questions were:

1. Does the level of burden of care among carers of patients with schizophrenia have impact on the level of expressed emotions?
2. Does the magnitude of perceived stigma in carers of patients with schizophrenia affect their level of expressed emotions?
3. Does the level of urbanisation of carers of patients with schizophrenia affect their level of expressed emotions?

1.2 The objectives were:

1. To compare the EE between carers of outpatients with schizophrenia living in urban and those living in semi-urban areas

2. To compare the EE between carers of patients with schizophrenia with high burden of care and those with low burden of care

3. To compare the EE between carers of patients with schizophrenia with high perceived stigma and those with low perceived stigma

Chapter Two

Literature Review

2.0 Introduction

This chapter provides background information and rationale for the thesis research. It discusses the concepts of schizophrenia, caregiving in the family, informal care among people with psychiatric illness, family burden, deinstitutionalization and caregiving in schizophrenia, experience of caregiving with family burden, stigma and schizophrenia, and the impact on informal carers of people with schizophrenia. The concept of expressed emotion and its relationship with schizophrenia is also discussed. Particularly, schizophrenia is described in relation to the diathesis-stress model and the family variables above are discussed in relation to their possible interactions and impacts on informal carers of people with schizophrenia. Within this context, this study as well examined the differential impact of these variables in the context of semi-urban and urban dimensions. These variables are hypothesized to be dynamic and to change as a function of different environments.

2.1 Schizophrenia

Schizophrenia is a chronic life changing illness that is characterized by significant impairment as the result of disordered thinking, disorganized behaviour, hallucinations, delusions, and negative symptoms such as affective flattening, poverty of speech, and lack of motivation (Brekke & Slade, 1998; Harding & Keller, 1998; Harding& Zahniser, 1994; American Psychiatric Association, 2000), and may eventually lead to the inward

transformation of self and outwardly to others the transformation of the person or his identity (Estroff, 1989).

Schizophrenia is considered to be one of the most severe forms of psychiatric illness with a worldwide prevalence of 1.4 to 4.6 per 1000 (Jablensky, 2000). Estimates of lifetime prevalence range from 0.63% to 3.8% (Bromet, Dew, & Eaton, 1995; Hafner and Heiden, 1997). Rates of schizophrenia incidence and prevalence are consistent across cultures (Bromet et al., 1995; Hafner and Heiden, 1997; Jablensky et al., 1992) though the incidence and prevalence of schizophrenia vary substantially across sites, with a higher incidence and prevalence among males, migrants, and those living in urban environments (McGrath et al., 2004; 2008, Saha et al., 2005). Worldwide, the median incidence of schizophrenia is around 1.5 per 10,000 inhabitants (McGrath et al., 2004), and the lifetime morbid risk of developing schizophrenia is near 0.7% (Saha et al., 2005). The incidence ratio for men to develop schizophrenia relative to women is 1.42 (Aleman, Kahn and Selten, 2003).

A more benign course of illness has been identified in developing countries as compared to developed countries (Leff et al., 1992), indicating that while social and cultural factors do not cause schizophrenia, they play a role in its course. Social and psychological factors are important predictors of the course of schizophrenia (Erikson, Beiser, and Iacono, 1998; Pindo and Munroe-Blum, 1985; Strauss and Carpenter, 1977). The burden of illness associated with schizophrenia is significant. It is the fifth leading cause of disability in developed countries, accounting for 4% of all disability among both genders, and 6% of al1 disability among women aged I5 to 44 years (Bland, 1998). In the last decade, it is sixth leading cause of years of life lived with disability in both sexes of all

ages; sixth leading cause of years of life lived with disability in low and middle income countries. Although, the incidence of schizophrenia is low, its early onset, long duration, and severe disability make it a leading contributor to the burden of disease in developing countries (Hyman et al., 2006).

The societal cost of schizophrenia is high. Across all ages, schizophrenia accounted for 1.4% of total health expenditures (Knapp, 2000). More than 5% total national expenditure in England in 1992-1993 was accounted for by schizophrenia alone. One five-country European study reported that family care-givers for adults with schizophrenia spent on average between 6 and 9 hours per day providing support (Magliano et al., 1998). A study of 408 families in the USA with a mentally ill family member (80% with schizophrenia) showed that care-giving absorbed most of their spare time (67 hours per month) with knock-on employment and financial difficulties (McGuire, 1991). Societal concern about violent incidents, homicides and suicides can be seen as a cost. Estimated contacts with criminal justice agencies in the USA by people with schizophrenia amounted to 464 million dollars (Rice and Miller, 1996). The direct costs of schizophrenia in the USA in 1990 amounted to 17 billion dollars, reflecting the high costs of institutionalization as well as the large number of ambulatory visits per person. This was 2.5% of the total national health care expenditure. The indirect costs estimates might be 3-4 times higher than direct costs (Andrews et al., 1985; Davies and Drummond, 1994). In England and Wales, the direct cost for schizophrenia was 2.8% of all NHS expenditure. These figures underestimated the value of care-giver time and did not look at the intangible consequences of the illness for quality of life.

The disease usually starts during the late teen years or early adulthood with three in four of all cases having onset in the 16-25 age group (Torrey, 1983). In the 16-30 year old range, more men were seen in the 16-20 year old range while more women were in the 25-30 year old group. After the age of 30, onset is less common and after 40 years, it is quite rare (Torrey, 1983). The reason for the late teen or adult onset of schizophrenia is not completely understood. Nevertheless, schizophrenia strikes its victims after years of adequate or normal functioning and its onset can damage the person's developmental trajectory and threaten the identity or core self of the teenager or adult (Jackson, McGorry, Edwards and Hulbert, 1996). In recent decades, schizophrenia has been found to be a biologically-based disorder, with altered activity in many parts of the brain including dopamine, GABA, and glutamate systems (Winterer, 2006). Specific areas of the brain have been particularly implicated and include the prefrontal cortex, anterior cingulate cortex, cerebellum, basal ganglia, and hippocampus (Fusar-Poli et al., 2007).

Several models have been propounded to explain schizophrenia, but research evidence has clearly supported a diathesis-stress model of schizophrenia in which environmental stressors interact with biological factors, triggering the onset of the illness and a recurrence of symptoms (Nuechterlein and Dawson, 1984; Walker and Diforio, 1997). The diathesis-stress formulations is useful to explain the contribution of genetic, neurobiologic, and environmental factors, including family EE (Hooley, 2007), to both the pathophysiology and course of schizophrenia (Ciompi, 1989; Nuechterlein and Dawson, 1984; Nuechterlein et al., 1994; Zubin and Spring, 1977). Zubin and Spring's model (1977) incorporates concepts of homeostasis, stress, and coping. Schizophrenia is understood as implying a relatively enduring state of vulnerability to stressors, and acute

episodes of schizophrenic disorder are understood as temporary states. Vulnerability may be innate or acquired. Once present, vulnerability is a relatively enduring trait, conceptually independent of coping ability. When endogenous or exogenous stresses exceed a person's vulnerability threshold, coping and adaptation is disrupted, and the person develops an episode of schizophrenia. In subsequent sections of this literature, EE, an exogenous stress, has been shown to disrupt coping and adaption of persons with schizophrenia. Nuechteriein et al.'s (Nuechterlein and Dawson, 1984; Nuechterlein et al., 1994; Nuechterlein, Snyder, and Mintz, 1992) model of schizophrenia relapse is an elaboration of the stress-vulnerability model of schizophrenia. The primary focus of their model is on explaining the clinical and social course of schizophrenia, not its aetiology. And this model has significant implications on the illness experience of persons living with schizophrenia because if these factors are modified, the quality of life of persons with schizophrenia would improve and subsequently the course of the illness could be mild.

According to this model, four classes of factors interact to modify the course of schizophrenia. These factors are classified according to whether they are personal or environmental and according to whether they are risk or protective factors. The four factors are 1) personal vulnerability factors - enduring genetic and psychobiological traits, such as autonomic nervous system hyper-responsivity; 2) personal protective factors, such as coping abilities, antipsychotic medication; 3) environmental potentiators and stressors, such as life events, family EE; 4) environmental protective factors, such as: social networks, and effective family problem solving. According to Nuechterlein et al. (Nuechterlein & Dawson, 1984; Nuechterlein et al., 1992, 1994), the four factors in

interaction may produce an intermediate state of autonomic hyperactivity, information processing overload, and deficient processing of social stimuli; a precursor state of prodromal symptoms of schizophrenia. The model includes a feedback loop among the four input factors and the prodromal symptoms. In other words, the prodromal symptoms may invoke changes in the protective or risk factors. For example, the prodromal symptoms may result in increased stress or they may trigger coping responses. Psychotic relapse occurs when and if the individual's threshold for psychotic symptoms is exceeded.

This study examined if there were urban-semi-urban differences in carer's burden of care, perceived stigma and EE.

In the past, family members of individuals with schizophrenia were blamed with causing the illness and the practice then was for their ill relative to be typically committed to an institution where s/he could be protected from the family and the rest of the society (Terkelsen, 1990). Historically, scholarly and clinical interest in families and schizophrenia focused on the family as an etiologic agent. Psychogenic theories of schizophrenia proposed through the 1940's to the early 1980's influenced negative professional and community attitudes toward families with a member with schizophrenia and had considerable impact on individual and family treatments for schizophrenia (Hatfield, 1987b; Mueser and Glynn, 1998). Their decreased influence in the professional literature over the past 20 years is attributed to lack of empirical evidence for the theories and associated treatments, accumulating evidence for a biologically weighted model of schizophrenia, and the success of support and advocacy groups in the developed countries in focusing attention on the problems and concerns of families (Hatfield, 1987b; Mueser and Tarrier, 1998; Tessler et al., 1987; Terkelsen, 1990). The family was

finally relieved of the blame and the guilt (Terkelsen, 1990) and families have been called the "safety net of last resort" for the persons with schizophrenia (Tessler, Killian, and Gubman, 1987).

At the initial onset of schizophrenia, family members of the proband often experience reactions of shock, distress, denial, anger guilt or fear. The initial diagnosis or hospitalisation can have a huge impact on family members as they are all too aware of the stigma and negative stereotypes that are attached to the group to which their relative may now belong. The family may also be aware of the possibility that schizophrenia can be a life-changing illness for many of those who suffer from it.

Research has shown that a significant proportion of patients discharged following an episode of schizophrenia return to family homes (Hatfield, 1987b; Mueser and Glynn, 1998). These families invariably continue the care of these discharged persons and support from them continues to be important, even for patients who do not live with their families (Tessler and Ganache, 1994). Family members can be critical sources of feedback to the individual with schizophrenia. Social and environmental factors such as perceived stigma, burden of care and EE among family members would thus have impact on discharged patients and those being managed on an outpatient basis. In this wise, family relationships remain important as they may have a negative or positive effect on the well-being of the person with schizophrenia, depending on the quality of the relationship. This study was set to examine the possible differential impact of these factors in different environments.

Many experts have argued that the treatment of choice for schizophrenia would include a combination of medication and psychotherapeutic intervention, with a strong emphasis on family psycho-educational interventions (Weisman de Mamani et al, 2009). For example, the Schizophrenia Patient Outcomes Research Team (PORT) regularly reviews a wide range of interventions and periodically releases a list of best practices treatment recommendations. Research from 20 outcome studies reviewed in the 2004 PORT report indicated that family interventions typically cut relapse rates by a significant fifty percent (Lehman et al., 2004). Based on these and other findings PORT concluded that family interventions for schizophrenia have strong empirical support. Thus, greater research and implementation of family based approaches are sorely needed. So it is imperative for professionals in the mental health field to develop a better understanding of the experience of family members of individuals with schizophrenia as it would help professionals to support families in dealing with schizophrenia and to maintain their well-being so they can contribute to the well-being of their ill relatives in a positive way. It is against this background that this study was set to explore if there were differences in factors such as perceived stigma, burden of care and EE in semi-urban-urban settings.

2.2 Care-giving in the family

Caregivers may be defined in many different ways. Caregivers vary in their relationship to the care recipient (spouse, child, professional); they may be the primary or secondary caregiver; they may live together with the care recipient or separately (Brodaty and Green, 2002). However, one thing that is common is that caregiving includes giving support and assistance to a family member who has special needs (Walker, Pratt and

Eddy, 1995). In this study, caregiving includes giving support and assistance to a family member with schizophrenia.

Home health care providers and other professionals are described as “formal” caregivers. They often undergo training and receive payment for their services that they tender to the care recipient (Health Plan of New York [HPNY] and National Alliance for Caregiving [NAC], 2000). Some formal caregivers are trained volunteers associated with an agency (HPNY and NAC, 2000). On the other hand, family caregivers are sometimes described as “informal”. Lubkin and Larsen (2006) say that it is a term that is employed by professionals to describe people who take on care-giving responsibilities without receiving any source of income and who usually have a personal bond to the person at the receiving end of care (for example, a family member or friend) (Lubkin and Larsen, 2006). This study is focused on exploring the experiences of family caregivers of people with schizophrenia.

HPNY and NAC (2000) stated that more than 44.4 million people who live in America provide informal care-giving to either friends or family members. The people involved are spouses, extended family members, partners, friends, neighbours, adult children and in extreme cases even small children. Hence, caregivers are of all ages. They mostly serve as informal caregivers and therefore do not receive payment for providing care. NAC and American Association of Retired Persons (AARP) (2004), reported that about 83% of caregivers are related to the people for whom they provide care.

Caregiving occurs across all socioeconomic strata and in all cultural groups. Caregivers come from every corner of the earth and from different walks of life (HPNY and NAC,

2000). The average age of a caregiver providing care to an adult or a person with a mental illness is 46 years but more than half of all caregivers range between 18 and 49 years old (HPNY and NAC, 2000).

The literature also suggests that majority of caregivers are women. Caregiving is often perceived as an exclusive purview of women because many of the demands of the sick people are often met by women in families (Walker and Pratt as cited in Lubkin and Larsen, 2006). Bedini and Phoenix (2004) reported that about 80 percent of people who provide informal caregiving are women. In the event where the spouse is absent, daughters or daughters-in-law are mostly the people who have to undertake caregiving responsibilities. HPNY and NAC (2000) asserted that on average women spend 17 years of their lives rearing their children and another 18 years as caregivers to elderly parents, and in some cases to people with mental illness. However, several studies have reported a trend of male caregivers that is burgeoning (Awad and Voruganti, 2008). In fact, these authors pointed out that according to some recent studies, 40% of caregivers are men.

2.3 Informal care among people with psychiatric illness

Since the mid-twentieth century there have been certain key themes in the psychiatric literature about informal carers. First, prior to the 1970s, the notion of the 'informal carer' did not exist (Heaton, 1999). Families were regarded as part of the pathology, especially in respect of schizophrenia (Fromm-Reichman, 1948; Lidz et al., 1957). Secondly, from the mid-1970s through the 1980s, the burden experienced by informal carers became a prominent research theme (Grad and Sainsbury, 1963; Hoenig and Hamilton, 1966; Hatfield, 1978; Pai and Kapur, 1981; Gibbons, Horn, and Powell, 1984;

Fadden, Bebbington, and Kuipers, 1987; Francell, Conn and Gray, 1988; Lefley, 1989; Schene, 1990; Kuipers, 1993). Thirdly, families came to be seen as having an active role in improving the wellbeing of the patient, with the development of psycho-educational strategies.

While support for family and friends is a usual part of family and community life, informal care extends beyond the scope of this simple support (Biegel, Sales and Schulz, 1991). Pearlin et al (1995) characterised informal care as consisting of "activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves", which implies that informal care extends beyond normative activity. More certainly, those who provide such care are readily able to distinguish care-giving from ordinary family or friendship responsibilities. Informal care can therefore be seen as 'extraordinary care' which is outside the boundaries of usual care though embedded in ordinary everyday relationships, and can come to dominate and restructure a relationship (Biegel, Sales and Schulz, 1991; Pearlin et al.,1995). Informal care is also distinct from 'formal care', which is care provided by qualified people in a professional capacity, working within particularly structured organisations (Van Agthoven and Plomp, 1989; Bond, 1992).

Within the scope of several perspectives, informal care has been defined and constructed in a number of ways. Such perspectives include the disciplines within which research has taken place, such as psychiatry, sociology, feminism, nursing praxis and economics, and according to informal carers themselves (Collings and Seminiuk, 1998). Of these various perspectives, of most relevance to this study are psychiatric and sociological perspectives, and those of informal carers themselves.

Most psychiatric research constructs informal care as support given by family members for those who are sick or dependent. Schene and colleague's (1994) definition captures this informal care in mental illness as taking place in the context of a "relationship between two adult individuals who are typically related through kinship", where one person takes on an unpaid, unanticipated responsibility for the other person, and where the reciprocity usually associated with adult relationships does not exist.

In sociology, the distinction between formal and informal care was first made in the 1950s. Following this discourse, the distinction has contained more perspectives such as those of political economy, social context, gender and the identity and characteristics of the carers. The distinction between family caregiving and other volunteer caregiving has been seen as important because the extent of responsibility and choice varies significantly between these contexts. Of relevance to this study, informal care emphasises the social and relational basis of the phenomenon and the transactions involved (Dalley, 1988). "Informal care is the assistance given on the basis of a personal relationship between the person seeking help and those in his/her immediate surroundings who offer help: the assistance of household members, family, friends, neighbours or volunteers" (Van Agthoven and Plomp, 1989).

Opinion about the 'best' definition of informal care varies to some extent according to discipline. The working definition of informal care used in this study is that informal care takes place in a relational context of commitment and attachment, and is provision of emotional, practical or financial support, accompanied by a feeling of responsibility, by people without a professional background in care-giving.

2.4 Concept of Family Burden

The concept of family burden has been discussed extensively in literature. However, there is lack of agreement on the precise definition as shown by a review of recent articles (Awad and Voruganti, 2008; Ohaeri, 2002; Tessler and Gamache, 1994). These authors argued that this concept obscures possible multidimensionality that it connotes in the social world and that it rather focuses on the negative aspects of looking after a relative with a chronic illness. Caring for persons with schizophrenia, for example, could be self-satisfying and accordingly, Awad and Vorunganti (2008) proposed that in order to highlight positive aspects of caregiving experience, the concept of 'burden of care' be changed to an unbiased term for example 'experience of caregiving'. However, the burden of care concept continues to be mostly used.

The most used definition of family burden in the literature is that of Hoeing and Hamilton (1966). Their definition distinguished between objective and subjective types of burden. The objective burden refers to the concrete factors that are seen to bring family life into disruption such as loss of income (Glanville and Dixon, 2005), disruption of daily routine (Magaña et al, 2007), social life and work (Thompson and Doll, 1982), disturbance of the well-being of the other family members, and in particular abnormal behaviour likely to cause distress (Samele and Manning, 2000). The subjective burden refers to experience or psychological or emotional impact of looking after an ill relative (Samele and Manning, 2000).

The dominance of the family burden model in research suggests that burden is the defining experience of families with a member with schizophrenia. The investigation of

the positive as opposed to the negative aspects of caregiving is thought to be a reductionist approach of psychological and social phenomena. Even the balanced investigation of positive and negative aspects would not overcome the limitation of the family burden model. By decomposing the experience of relatives - positive experiences vs. subjective burden vs. objective burden - it does not provide a means to ask about the experience in its entirety.

Family burden models and research apply stress theory, a psychological theory of individual adaptation (Lazarus and Folkman, 1984), to the understanding of relatives' experiences of schizophrenia in a family member. Several representations of stress models of family burden have been proposed (Maurin and Boyd, 1990; Schene, 1990). One of such (McCleary, 1996) shows that within the stress, appraisal, and coping model, family burden can be viewed as both a stressor and an adaptational outcome for the relative.

In the McCleary's (1996) model, changes in the patient's behaviour, social functioning and social role performance as a result of schizophrenia, financial costs of supporting the ill relative, perceived "loss" of the former healthy relative and interactions with the health care system are illness related stressors. Objective burden is the direct result of these illness related stressors and does not depend on the relative's perception that the changes are stressful. Subjective burden, the emotional impact or distress caused by schizophrenia in a family member, is an adaptational outcome of the relative, their psychological well-being. It requires cognitive appraisal by the relative that schizophrenia in a family member is stressful. Within the stress, coping, and adaptation framework, individual differences in family burden and changes in family burden over the course of

schizophrenia may result from: individual differences in the severity of the expression of schizophrenia; relatives' differences with respect to appraisal of the impact of schizophrenia; differences in relatives' personal and environmental resources and; differences in constraints on relatives' use of resources, e.g., perceived stigma. In this study, the question was whether or not there was difference in the composite family burden in terms of difference in the environment. Furthermore, the study sought to clarify whether or not those with high or low family burden expressed distress such as EE differentially.

2.5 Deinstitutionalization and Informal Care-giving for Patients with Schizophrenia

Traditionally informal carers of the mentally ill are defined and identified by mental health professionals or by researchers. However, there are other potential sources of defining and identifying informal carer such as through patient records and patients themselves. In most cases, informal caregiving is based on a pre-existing personal relationship between the caregiver and the patient (van den Berg, Brouwer, and Koopmanschap, 2004). In the majority of informal carer researches, including schizophrenia, only one informal carer is studied for each index patient though this might underestimate what is known about social support and social networks. This study will align with this approach.

In many western countries, psychiatric asylums have been closed down. Most of the hospital beds have gradually been reduced with the intention of integrating patients with psychoses into society. This deinstitutionalization is a major factor associated with family caregiving in major psychotic disorders particularly in schizophrenia (Nordentoft et al.,

2010). Lamb and Bachrach (2001) posit that deinstitutionalization generally consists of three component processes: (1) The release of mentally ill people from psychiatric hospitals to alternative facilities in the community, (2) The diversion of potential new admissions to alternative facilities, and (3) The provision of special services for the care of mentally ill people who are not in state hospitals.

Deinstitutionalization is a policy, made possible by strong political leadership, lobbied by human rights organizations, and caring family members (Lamb and Bachrach, 2001). It came about in the context of attempts to abolish the inhumane treatment that mentally ill individuals used to endure in state institutions and highlighted awareness of the humanity and needs of mentally ill persons. Moreover, it has also shifted an exclusively biological ideology of psychiatry by drawing attention to the complex interface between biological, psychological, and socio-historical events that affect the lives of people with mental illness (Engel as cited in Lamb and Bachrach, 2001).

Within the discourse of deinstitutionalization, there were also theoretical changes in how professionals understood the role of families in certain mental disorders. For example, in the case of schizophrenia there were many family theories (e.g. double bind theory, symbolic studies, communication deviance studies) that gained credence during the earlier period of wide scale deinstitutionalization. Though there were a few family studies that took place prior to deinstitutionalization, most such studies took serious momentum at the height of the deinstitutionalization process. A plethora of these family studies became prominent between the 1960s and the 1980s. These family studies were in concert with the enshrined goals in the policies of deinstitutionalization.

Family studies broadened the focus from people with schizophrenia to considering their families as well. Deinstitutionalization brought with it new challenges for families. Whereas in the past many family members had suffered at being excluded from the lives of their institutionalized relatives, now families had to face the challenge associated with having their relatives living at home. In addition, in the early days of family theories, the families had to contend with the challenges of being blamed by mental health professionals for causing the illness of their relatives.

This deinstitutionalization has also led to an increased burden for the carers of patients in many countries (Honkonen, Saarinen, and Salokangas, 1999; Nordentoft et al., 2010; Rantanen et al., 2009; Ryu et al., 2006). Deinstitutionalization has hardly developed though in sub-Saharan African. While a wide range of literature exists of informal caregiver burden in other medical conditions, there are limited reports on psychotic disorders and particularly there are fewer studies on the size of burden associated with informal caregiving in schizophrenia (Dixon, 1999; Pharoah, Mari, Rathbone, and Wong, 2010; Flyckt et al., 2011).

The impact of most chronic disorders has been found to go beyond the functional and social impairment, together with unpredictable and sometimes risky or hostile behaviour (Ochoa et al., 2008). This impact extends to and strains the families of the patients. Yet the family burden of schizophrenia, its social and mental consequences and its specific features are still largely unknown (Awad & Voruganti, 2008). This study therefore attempted to examine the family burden of schizophrenia and its social consequences in semi-urban and urban communities in Nigeria.

The majority of informal care is given by relatives, particularly women in community based studies in Western countries (Schofield et al., 1998). According to these authors, the women are mainly daughters caring for their parents. However, men do provide, especially for their disabled wives or partners (Schofield et al, 1997). Among informal carers self-identity is an important concept. Once carers consciously find their self-identity in care-giving, they become both more demanding of services and more accepting of support, adopting a position between that of a naive lay perspective and a professional carer (Twigg and Atkin, 1994; Taraborrelli, 1994). Apart from these roles, carers who self-identify may be more able to move to a greater sense of mastery, and to make more space in their lives for their own needs unrelated to the caring role (Mitchell, 1996). These adaptations in turn may be related to better health and wellbeing for informal carers.

In the early 1980s, a catchment area study of people with schizophrenia and their families carried out in Southampton, England, revealed certain key findings related to informal carer mental health and experience of caring (Gibbons, Horn and Powell, 1984). About three out of four of the informal carers had symptoms of emotional or physical ill-health. The more severe their psychological morbidity the more they experienced burden or strain. The carer strain/burden was not associated with the carer age (over or under age 45), carer sex, relationship to patient or carer social class. However, the carer strain/burden was moderately correlated with total patient symptom score.

The Southampton study above had a number of strengths that make it one of the key studies in this area. First, an operationalized and inclusive definition of informal carer was used, which differentiates it from the few other studies done around this time (and

many of those done since). The investigators also used a highly operationalized definition of schizophrenia, the Present State Examination (9th edition), with ICD-9 diagnoses generated by CATEGO software (Wings, Cooper and Sartorius, 1974). In addition, they took a pragmatic approach to the assessment of burden by using the Social Behaviour Assessment Scale (SBAS) (Platt et al., 1980). SBAS is a standardised semi-structured carer interview measure which yields a robust assessment of the carer's experience of disturbed behaviour and social disability in the past month, the social role performance of the index patient, and the index patient's effect on the carer's health, on any children living in the household and other household circumstances such as financial hardship and disruption in the household. The SBAS captures both objective and subjective elements of burden.

Recently, Roick and colleagues (2007) found that family burden was associated with patients' symptoms, male gender, unemployment and marital status, as well as caregivers' coping abilities, patient contact and being a patient's parent. These authors argued that the burden on relatives of people with schizophrenia may be influenced not only by patient and caregiver characteristics but by social factors such as national differences in mental healthcare service provision. They found that when patient's and caregiver's attributes were controlled for, British caregivers reported more burden than German caregivers. This study aligned with the argument of these authors and posited that there would be variation in burden of informal care along semi-urban and urban dimension.

2.6 Experience of care-giving and family burden in schizophrenia

The majority of studies of carers of people with schizophrenia over the past thirty years have focused on variations on two themes. These are: first, identifying the predictors of burden; and secondly, informal carer mental health status in terms of patient clinical characteristics and carer psychological characteristics. It is important to note that many of these studies had methodological problems. In a comprehensive review by Baronet (1999), only 28 studies on caregiver burden in mental illness met the predetermined criterion for validity of measurement. When this author used the preferred standard of demonstration of concurrent or construct validity, all the studies reviewed were compromised by problems with validity.

In a landmark study Hoenig and Hamilton (1966) separated the burden construct into distinct subjective and objective elements. These authors regarded "any type of abnormal behaviour in the patient which was likely to be disturbing to others" and the observable costs or disruptions to daily life associated with this as objective burden. On the other hand, they regarded subjective burden as the carer's own view of the extent to which they have been burdened and his or her emotional reactions to care-giving. Until the last two decades, the validity of this dichotomy was assumed in most studies of informal carer burden (Pai and Kapur, 1981; Coyne et al., 1987; Noh and Avison, 1988; Tessler and Gamache, 1996). This study explored, using a valid scale, the differentials of both objective and subjective domains of burden in carers of people with schizophrenia living in urban and rural settings.

There has been emergence of common themes about burden in informal carers of people with schizophrenia despite lack of agreement about what constituted burden, problems of varied approach to the measurement of burden, the varied approach to the inclusion of non-kin carers and other methodological variations (Perring, Twigg and Atkin, 1990; Maurin and Boyd, 1990).

Burden of care has been associated with the meaning attributed to caring by the carer (Reinhard et al. 1994), with the experience of gratification, and with informal carers having more contact with mental health services, independently of patient status (Winefield and Harvey, 1994; Schene, van Wijngaarden and Koeter, 1998). It has been associated though variably with whether carer and index patient share a household (Jones, Roth and Jones, 1995).

Informal carer burden has been positively associated with low carer educational attainment, being female, the nature of relationship to index patient, for example being married to index patient, and carers being older (Brown, Birley and Wing, 1972; Noh and Turner, 1987; Winefield and Harvey, 1993; Cook et al., 1994; Greenberg, Kim, and Greenley, 1997; Magliano et al., 1998). Burden in parents has been positively associated with the family's developmental stage - that is, how much the need to care conflicts with parental expectations about the psychosocial development of the index patient (Cook et al., 1994; Pickett, Cook and Cohler, 1994). Burden thus would bear an important relationship to reactions of the carers to their relatives with mental illness. Scazufca and Kuipers (1998) found this relationship between burden of care and expressed emotions in their study, in which relatives of inpatients with schizophrenia who changed from high expressed emotions to low expressed emotions showed reduction in overall burden.

Aside from positive associations with some variables mentioned above, burden has also been found to be inversely associated with strong carer social networks, availability of social support and a wide repertoire of adaptive coping skills (Grad and Sainsbury, 1968; Fadden, Bebbington and Kuipers, 1987; Noh and Avison, 1988; Schene, 1990). In terms of index patient characteristics, burden has been associated with patient male sex (Fadden, Bebbington and Kuipers, 1987), longer duration and severity of illness (Thompson and Doll, 1982), social disability, negative symptoms and disturbing behaviours (Fadden, Bebbington and Kuipers, 1987; Noh and Avison, 1988; Winefield and Harvey, 1993; Schene, van Wijngaarden and Koeter, 1998). A few studies, however, have reported associations with positive symptoms (Brown, Carstairs and Topping, 1958; Grad and Sainsbury, 1963; Wing et al., 1964).

It is important to note that there is a contextual and cultural bias inherent in the cited literature above because the majority of the studies were done in England and North America. The experience of burden has been said to be culturally determined (Fadden, Bebbington and Kuipers, 1987; Raj, Kulhara and Avasthi, 1991; Magliano et al., 1998). This experience of burden may also be related to other social aspects such as rural and urban settings. This was the purpose of this study. It was set to examine if there were distinct variances in the experiences of burden of care depending on the type of social environment.

Objective burden was better understood by Noh and Turner (1987) as a stressor in the area of informal care of the elderly. This burden places demands on informal carers and in turn leads to the experience of stress and evokes a variety of coping strategies. One could extend this sequenced stress-response model such that burden of care in the context

of social factors such as perceived stigma would place demands on carers and in turn lead to experience of stress with consequent differential expressed emotions according to type of resident community.

2.7 Stigma and schizophrenia

It is customary to commence discussions of stigma with reference to Erving Goffman's seminal work on the subject. Goffman (1963) described stigma as an attribute that is deeply discrediting. He described how possessing the stigmatising attribute fundamentally intrudes on how others perceive the individual. In the ensuing transaction, the person with the attribute subsequently internalises the associated discredit thereby changing his or her own perception of the attribute. The stigmatised person feels he has been transformed from a normal to a tainted person. For example, the person with the attribute may start to anticipate discriminatory behaviour from others and may experience a reshaping of their emotions and beliefs about themselves and society. Goffman also described how the stigma process could extend to other people without the attribute but who are connected to the stigmatised person (e.g. relatives and psychiatric professionals). He referred to this as courtesy stigma.

Since Goffman's work, other researchers have extended the characterisation of stigma. Of the several types of stigma that have been described, the concepts of Enacted and Perceived stigma described by Jacoby (1994) appear relevant in this thesis. These two types of stigma are particularly important in understanding the impact of stigma on affected individuals or to other people without the attribute but who are connected to the stigmatised person (e.g. relatives) and in thinking of appropriate interventions.

According to Jacoby (1994), enacted stigma describes the actual experience of negative and discriminatory behaviour by others against the person with the stigmatising attribute. This could be extended to their relatives. The resulting distress in the affected individual is clearly linked to an actual experience of ill-treatment. Thus interventions to reduce enacted stigma would be more effective if directed at changing the negative and stereotypical attitudes of the perpetrators.

Having described enacted stigma thus, Jacoby (1994) described perceived stigma as a subjective belief or anticipation that having the stigmatising condition will lead to discrimination by others. The belief may be related to previous experiences of enacted stigma or may not be founded on actual experience (Scrambler 2004). According to Heatherton and colleagues, even when the stigmatizing attribute is not obvious, those who perceive themselves to be stigmatized often experience psychological distress and have a negative view of themselves (Heatherton, et al., 2003). It is as if the affected persons develop a different view of the world and different way of interpreting events and experiences influenced by possession of the stigmatizing attribute (Scambler, 2004).

Perceived stigma can have serious disabling consequences due to the tendency by affected individuals to take, sometimes, extra-ordinary measures to conceal their attribute (Scambler, 2004; Scambler and Hopkins, 1986). By extension, in the relatives/informal carers of those with stigmatising attributes, they would attempt to conceal these attributes in their ill person(s) or their association with their ill person(s). Typical consequences of these efforts to avoid disclosure include isolation and loss of social and economic opportunities (Leary et al., 1998). The importance of recognising perceived stigma lies in the potential for psychosocial treatment. For example, because the underlying mechanism

in perceived stigma may involve distorted cognitive appraisal, the associated psychological distress and avoidance could be amenable to Cognitive and Behavioural Therapy (Kent, 2000). These family carers are helped by attending groups consisting of other carers.

The impact of perceived stigma can be serious on affected persons. Even for life threatening diseases, perceived stigma could lead affected individuals to make deliberate and seemingly irrational decision not to seek help (Sadavoy et al., 2004). Consistent with Goffman's work, both enacted and perceived stigma can also apply to third parties with links to the stigmatized individual (courtesy stigma). However, it is important to recognize that despite the possibility of more negative self-appraisal by some stigmatized persons or their linked relatives or informal carers; this is by no means universal. On the contrary, other stigmatized persons or their informal carers show resilience and are able to ward off negative threats to their self-esteem (Heatherton, et al., 2003).

Stigma is a ubiquitous and diffuse concept (Weiss et al. 2001), which lends it use to a wide range of diverse processes that have in common a sense of social rejection (Coker 2005). Related concepts, which are sometimes used loosely to infer stigma include, social rejection, negative attitude, prejudice, discrimination, and social embarrassment. Also stigma has cultural and situational dynamism; hence what is considered stigmatizing in a particular historical or cultural context may not be at a different time or place and could even become a positive attribute. This study examined if perceived stigma differs among informal carers of people with schizophrenia in different places.

2.7.1 *Stigma dimensions*

Stigma dimensions predict how others are likely to respond to the possession of a potentially stigmatising attribute. Thus these dimensions help to understand why certain attributes and not others become stigmatising. Katz (1981) and Jones et al (1984) described several interrelated stigma dimensions including: Visibility, Threat or Peril, Chronicity, Responsibility, and Disruptiveness.

The dimension "Visibility" refers to the extent the attribute is obvious, concealable, or aesthetically challenging to others. In general, stigma theory predicts that the more visible and disfiguring an attribute the more stigmatising it is likely to be. Some people with schizophrenia have easily recognisable behavioural manifestations of illness such as positive symptoms and aggression which increase the potency for stigma. This visibility for schizophrenia is more likely in developing countries like Nigeria. For example, the onset of a psychotic episode in Low and Middle Income Countries (LMIC) is more likely to be linked to episodes of assaultive behaviour or contact with police than in a High Income Countries (HIC) (Temmingh and Oosthuizen 2008; Volavka et al., 1997).

The stigma dimension of "Threat or Peril" is to do with the perceived danger posed to others by virtue of a person possessing the attribute. People with schizophrenia have been reported to be more liable to commit crimes than the general population (Swanson et al., 2006; Meehan et al., 2006; Lambertti, 2007). Analyses of trends in the last decade have faulted the assumption that there is a positive relationship between endorsing biological causes and acceptance of people with mental illness (Angermeyer and Matschinger, 2005; Bag, Yilmaz, and Kirpinar, 2006). Consistent with this dimension, it is well

recognised that beliefs that people with schizophrenia are dangerous are stigmatising. Furthermore, in some non-Western societies such as in Nigeria, inaccurate beliefs that associate schizophrenia with peril are still common. For example, most studies have concluded that inaccurate views about causation are strongly associated with stigmatizing attitudes to mental illness including schizophrenia (Gureje et al., 2006; Haghighat, 2001; James, 1998).

The dimension of "Chronicity" predicts that long lasting conditions would be more stigmatising than acute short-lived disorders that leave no permanent marks. Schizophrenia is essentially a chronic life-long disorder with only a small chance of cure for a minority of affected persons. Although some affected persons are able to enjoy prolonged periods of good health, the underlying genetic vulnerability does not change.

The stigma dimension of "Disruptiveness" describes the extent to which possessing the attribute interferes with interpersonal relationships. Disruptiveness is also related to other dimensions like Chronicity, as more severe and long-standing disorders tend to be also more disruptive.

The dimension of "Responsibility" refers to the assumption that people are more likely to experience stigma if they are considered in some way personally responsible for acquiring the negative attribute. Although people affected by schizophrenia are clearly not responsible for acquiring the disorders, in communities where misinformation about the disorder is prevalent, affected persons may be blamed unfairly. In urban dwelling, people believed in the biopsychosocial cause of mental illness such as schizophrenia while in rural dwelling the cause was supernatural (Adewuya and Makanjuola, 2008). In

these rural dwellings, affected persons and their families (including their informal carers) may be blamed unfairly and thus stigmatised more than in urban dwellings.

2.7.2 *Courtesy stigma*

Relatives of a person with the stigmatizing attribute can experience "courtesy stigma" (Goffman 1963). Courtesy stigma is known to worsen the subjective burden of care on relatives. Fear of courtesy stigma results in concealment and secrecy, which limits access to family support (Hinshaw 2005).

In conditions like schizophrenia, parents and siblings are more likely to receive courtesy stigma (Hinshaw 2005). Parents may be unfairly blamed by their immediate community (Sankar et al. 2006; Burnes et al 2008) or blame themselves resulting in high levels of guilt (Murray 1976).

2.7.3 *Stigma and mental illness*

Over the past 15 years, there has been a substantial increase in research on mental illness as it relates to stigma (Weiss, Ramakrishna and Somma, 2006; Major and O'Brien, 2005). In their review, Brohan and colleagues (2010) reported that in this relationship, the stigma concept had been criticised to be too individually focused and loosely defined. And in response to these criticisms, Link and Phelan (2001) have defined stigma in its relationship to mental illness as 'the co-occurrence of its components: labeling, stereotyping, separation, status loss, and discrimination' in a context in which power is exercised. This definition covers the length and breadth of the stigma dimensions as explained by Katz (1981) and Jones et al (1984).

Another area of importance in the relationship of mental illness and stigma is in the possible intersection of stigma and prejudice approaches. Phelan and colleagues (2008) have recently investigated this possible intersection and have concluded that the two approaches have much in common with most differences being a matter of emphasis and focus. They argue that stigma and prejudice have three functions: exploitation and domination (keeping people down); disease avoidance (keeping people away) and norm enforcement (keeping people in).

Another important framework is the definition of stigma by Thornicroft et al, (2007). They revised Corrigan's framework in which stigma is categorised as either public stigma or self-stigma. Corrigan (2005) further broke down each of these two areas into three elements: stereotypes, prejudice and discrimination. However, in the definition of Thornicroft and colleagues (2007), stigma as it relates to mental illness includes three elements: problems of knowledge (ignorance or misinformation), problems of attitudes (prejudice), and problems of behaviour (discrimination).

2.8 Impact of stigma on informal carers of people with schizophrenia

In contrast to earlier studies that claimed that stigmatizing attitude towards the mentally ill might be less evident in Africa (Fabrega, 1991), recent researches in the last decade have shown that there is high stigmatizing attitude towards the mentally ill both by the general community (Adewuya and Makanjuola, 2008; Gureje et al., 2005) and health practitioners (Adewuya and Oguntade 2007; Adeyemi et al., 2002).

Literature on mental illness stigma is less in sub-Saharan African than in the western countries. In sub-Saharan Africa, available studies have all been limited to public stigma

and self-stigma as regards people with mental illness. These researches have shown that self-stigma and fear of rejection by others result in many people with mental illness not being able to pursue life opportunities for themselves (Lysaker et al., 2007; Link et al., 2001).

There are much fewer studies on courtesy stigma and how it impacts on the quality of life of people with mental illness and their informal care givers. Further research is needed to determine the extent of needs and difficulties of primary caregivers caring for family members with schizophrenia. Western studies have indicated mixed findings about the amount of stigma experienced by participants. For example, while Asai (1983) found that 66 percent of Japanese families were 'paying no attention' to what others thought about the behaviour of their relative with a mental illness, suggesting a lower level of stigma, others, in contrast, have suggested that stigma is high (Ryder, Bean and Dion, 2000; Kadri et al., 2004: all cited in Rooney, Wright and O'Neil, 2006). Much work needs to be done in this sub-Saharan region in the area of courtesy stigma and its impact on the ability of people with schizophrenia to pursue life opportunities, as well as family burden and expressed emotion.

Perceived legitimacy of discrimination and group identification are two factors that influence how people with self-stigma would respond to public stigma (Corrigan and Watson, 2002). The authors argued that if people with mental illness perceived discrimination as legitimate, they were likely to have low self-esteem. If however they regarded discrimination as unfair, their reaction to perceived discrimination would depend on the level of identification with the group of people with mental illness. This study was set to examine if informal carers of people with schizophrenia have high self-

stigma as found the in studies of people with schizophrenia (Adewuya et al., 2010; Adewuya and Makanjuola, 2008; Botha et al., 2006; Gureje et al., 2005)? And would their response to courtesy stigma reflect high burden and emotional reactions to their relative with schizophrenia? What would be the correlates of high self-stigma in informal carers? Would it include level of social support, employment status and duration of illness as found in studies of people with schizophrenia (Adewuya et al., 2010; Verhaeghe et al., 2008)?

2.9 Expressed Emotion and Schizophrenia

Following deinstitutionalization failures in England, researchers at the MRC Social Psychiatry Unit were interested in understanding factors which contributed to deinstitutionalization failures and the course of schizophrenia (Leff and Vaughn, 1985; Brown, 1985). A series of follow-up studies of discharged patients with schizophrenia, found that patients returning to live with spouses or parents had worse outcomes than those discharged to lodgings or to live with siblings and that readmission was related to the kind of home to which they were discharged. Subsequently, researchers focused on identifying reasons for poor clinical outcomes and studied patients in families.

These researches identified measures of family "emotional involvement". This “emotional involvement” called expressed emotion (EE) was developed in 1976 by Vaughn and Leff in their work with families of people with schizophrenia and is a composite of measures of criticism, hostility, positive comments, emotional over-involvement and warmth (Vaughn and Leff, 1976, 1985). This EE concept is an elaboration of Sullivan’s idea (1947) that emotion creates an atmosphere within which

social interaction occurs and also a development of low and high involvement homes (Brown, Carstairs and Topping, 1958; Rutter and Brown, 1966; Wearden, 2000). Thus it relates not only to the emotional climate of interpersonal relationships but also to a dichotomous "global index of emotions, attitudes and behaviours" (Jenkins and Karno, 1992) expressed by relatives and other carers in a range of clinical situations, which reflect their "emotional attitude" to the patient (Vaughn, 1999). High EE is one or both of emotionally over-involved and critical interaction styles rated over a specified threshold in a standardised rating process.

EE was found to predict clinical deterioration and was associated with relapse. The association between EE and relapse was shown to be independent of medication compliance (Brown, 1985). Since it was first identified (Brown, Birley and Wing, 1972), the finding that high EE in the family environment is predictive of relapse in the first 9 to 12 months following discharge from hospital following a schizophrenia psychosis has been replicated in a variety of countries and cultures (Bebbington and Kuipers, 1994a). Reduced time in face-to-face contact and regular use of antipsychotic medication were associated with reduced risk of relapse in what were defined as high EE homes. Hence, high EE in carers (Moore, Ball and Kuipers, 1992; Kuipers, 1995) reflects a psychologically stressful social environment for patients with a range of mental and physical disorders (Szmukler et al., 1987; Hooley, Orley and Teasdale, 1986; Miklowitz et al., 1988; Hooley, 1999; Bledin et al., 1990; Vaughn, 1989, 1999; Kuipers, 1979; Wedell, 1987; Miklowitz et al., 1989; Barrowclough, Johnston and Tarrier, 1994; Wearden, 2000). EE in carers is a robust predictor of clinical outcome in those with schizophrenia (Kavanagh, 1992; Bebbington and Kuipers, 1994) independent of factors

such as the duration of illness, the severity of the patient's symptoms and behavioural disturbance.

Much research has treated EE as if it is a trait (Barrowclough, Johnston and Tarrier, 1994). It was argued that it related to the personality style of informal carers, and it interacts with the psychopathology of the person with schizophrenia (Brown, Birley and Wing, 1972). It has been reported by some researchers as a relatively stable characteristic over nine months (Favre S. et al, in Bebbington et al., 1995) and five years (McCreadie et al., 1991). However, it has been noticed that a small intermediate group move between low and high EE status, which may mean that some carers alter their EE status according to how stressed they are (Bebbington et al., 1995). It is therefore likely that EE is best considered as a characteristic that can change (Kavanagh, 1992; Falloon, 1988; Goldstein et al., 1992). Thus there is a complex circular relationship between EE and patient relapse, whereby the patient's clinical state affects the informal carer's EE level, which then feeds back to influence the patient's clinical state (Leff and Vaughn, 1985; Bebbington et al., 1995; Hooley and Richters, 1995).

In addition, researches have found association of EE with a range of other informal carer characteristics and this raises the possibility that it is a marker of informal carers' attributions about the illness. For instance, high EE is associated with anxiety and fears in relatives who do not attribute patients' problems to illness (Greenley, 1986). Compared to relatives with emotional overinvolvement, relatives who are more hostile and critical attribute more of the patient's difficulties to factors personal to and controllable by the patient. These could be related to high burden and perceived public stigma. For instance, high EE has been associated with higher carer subjective burden (Scazufca and Kuipers,

1996; Wagner et al., 1997). This could be explained by the finding of Barrowclough and colleagues (Barrowclough, Tarrier and Johnston, 1996; Barrowclough and Parle, 1997) that the cognitive appraisal of the illness and caring experience (attributions), which could include courtesy stigma, are related to EE and to carer distress (Schene, van Wijngaarden and Koeter, 1998). Relatives with emotional overinvolvement are more like low EE relatives, in that the patient's problems were more likely to be seen as universal or not under the patient's influence (Barrowclough, Johnston and Tarrier, 1994; Brewin et al., 1991; Weisman et al., 1993; Leff, 1994; Hooley and Licht, 1997). This study sought to examine whether or not different social environment such as semi-urban/urban settings play a significant role in this relationship.

Contemporary EE research since late 20th century has begun to focus on understanding why relatives and other carers may show high EE, on exploring such issues as personality and EE and the relationship between EE and stress and carer mental health, and informal carer attributions about the illness of the care recipient (Vaughn, 1999). Despite this, its relationship with different environmental settings of the informal carers has been little explored particularly in sub-Saharan Africa.

Needless to say, the theoretical models of families and schizophrenia revealed that EE and family burden models differ with respect to their perspectives on where problems are located within the family and how outcome is defined. EE focuses on patient outcome and family burden on family outcome. Thus the EE paradigm locates family as a problem as opposed to the paradigm of family burden which posits that the family has a problem. Both models are compatible when unified by stress and coping theory (the stress-diathesis model) where neither the family nor the patients are the outcome or the

problem. With this underlying unifying framework, the reciprocal effects between relatives and persons with schizophrenia would more likely be recognized.

2.10 Summary

In essence, family burden has been described as the defining experience of families with a member with schizophrenia. The impact on people with schizophrenia has been discussed as well. The relevance of courtesy stigma in defining the experience of families with a member with schizophrenia is recognized in the literature. The interaction of courtesy stigma and family burden, however, has been little explored. Within the diathesis-stress model, the interplay of these family variables with expressed emotion has been considered. It is not clear whether the level of burden of care impacts positively or negatively on expressed emotions in Nigerian informal carers with a member suffering from schizophrenia. Furthermore, it is not clear how courtesy stigma interacts with expressed emotions in these families. These are areas that this study is set to examine. How these family factors also operate in different social environment such as in semi-urban and urban settings in Nigeria is worth studying. This clarification of the possible differential impact of rural and urban settings on variables important in defining positive or negative experiences of families with a member with schizophrenia is necessary. First, it will allow a better grasp of the influence of the environmental dimension on expressed emotion, courtesy stigma and family burden. Perhaps it will pave the way for the understanding of how the social environment interacts with these family variables to impact on their experiences of caregiving. This could inform the development of more effective interventions for schizophrenia.

Chapter Three

Methodology

3.0 Introduction

This chapter deals with the research design and methodology. This study was carried out in two different settings – in Ile-Ife, the rural setting and in Lagos, the urban setting. Each phase explored family variables such as expressed emotions, perceived stigma and family burden among informal carers with a member with schizophrenia. The procedure of obtaining ethical approval, consent, administration of questionnaires as well as data analysis is described here.

3.1 Setting of the Study

The study was conducted in two settings – urban and semi-urban/rural. The urban setting was Lagos, and the participants were recruited from the adult outpatient psychiatric clinic of Lagos State University Teaching Hospital (LASUTH), Ikeja. LASUTH psychiatric clinic provides psychiatric services to the people of Lagos State mainly and has a catchment population of about 15 million people.

The semi-urban/rural setting was in Ile-Ife and participants were recruited from the adult psychiatric clinic of Obafemi Awolowo University Teaching Hospitals Complex (OAUTHC), Ile-Ife, which provides psychiatric services to Osun, Ekiti, Ondo and neighboring states in south-western Nigeria, which are predominantly Yoruba speaking with a catchment population of about 10 million people (National Population Commission 1998).

3.2 Study design: Cross-sectional study

3.3 Ethical Approval:

The ethical approval for this study was obtained from the Ethics and Research Committees of LASUTH, Ikeja and OAUTHC, Ile-Ife.

3.4 Participants:

To participate in the study, each patient was required to meet the following criteria: (1) above 15 years old; (2) out of hospital for at least 6 weeks and considered stabilized by his or her treating psychiatrist; (3) living with a close relative i.e. they have to be living with their parents or other relatives ; (4) an ICD-10 [International Classification of Diseases (1992)] diagnosis of schizophrenia without evidence of organicity, significant intellectual handicap, or primary diagnosis of substance abuse; (5) a minimum global assessment of functioning rating over 30 [on a scale from 1 (worst functioning) to 90 (superior functioning)]. The caregiver should be English speaking, and have no history of major mental illness.

With the cooperation of the patient's principal therapist, each patient was approached by an interviewer during an ordinary outpatient clinic visit. After the interviewer described the study, each patient was invited to sign an informed consent form that includes permission to contact the patient's relatives.

3.5 Sample Size:

Hundred patients and their 100 relatives were recruited randomly; 50 from the adult outpatient psychiatric clinic of Lagos State University Teaching Hospital (urban area)

and 50 from the adult outpatient psychiatric clinic of Obafemi Awolowo University Teaching Hospitals Complex Ile-Ife (semi-urban/rural area).

In each center on each clinic day, the total number of people with schizophrenia for appointments constituted the sampling frame. A table of random numbers was be used to select patients from the sampling frame. This continued until the sample size is reached. And the index patients identified their carer who were approached and recruited for the study.

3.6 Assessment:

I. Socio-demographic schedule (Appendix I) developed by the author for this study
II. Two indices of illness chronicity were assessed: (1) frequency of hospital admissions and (2) duration of illness from the 1st hospital admission.
III. EE ratings for relatives were assessed by The Family Questionnaire (FQ)
IV. The Perceived Devaluation and Discrimination Scale (PDD) was used to measure perceived stigma among the caregivers.
V. Burden Interview Schedule (BIS) was used to assess the burden of care in caregivers of patients with schizophrenia.

3.7 Instruments:

3.7.1. The Perceived Devaluation and Discrimination Scale (PDD):

The PDD (Appendix III) is a 12-item, uni-dimensional, scale which measures the extent to which a person believes that most people will devalue or discriminate against someone with a mental illness (Link, 1987). It asks about the extent of agreement with statements

indicating that most people devalue current or former psychiatric patients by perceiving them as failures, as less intelligent than other persons, and as individuals whose opinions need not be taken seriously. The measure captures a key ingredient of stigma theory—the extent to which a person believes that other people will devalue or discriminate against someone with a mental illness.

The scale is balanced such that a high level of perceived devaluation and discrimination is indicated by agreement with six of the items and by disagreement with six others. Items are appropriately recoded so that a high score reflects a strong perception of devaluation-discrimination. The scale is scored by summing all the items and dividing by 12. In six of the items the scoring of item is reversed in creating a sum score. The scale ranges from 1 to 6. Higher scores indicated stronger perceived devaluation and discrimination. Statements that mentioned actions measured discrimination (seven items). Statements about beliefs measured devaluation (five items).

This scale has been widely used and has excellent psychometric properties (Link et al., 1991). It has been used in developing countries such as Ethiopia and Nicaragua (Alem et al. 1999; Penayo et al. 1988; Shibre et al. 2001; Shibre et al. 2003).

3.7.2. Burden Interview Schedule (BIS):

This (Appendix IV) is a 24 item instrument developed by Pai and Kapur, (1981) for measuring objective burden in 6 domains which include, effects on family finances, effects on family leisure, effects on family interaction, effects on the physical health of family members, and effects on mental health of other family members. The last question is with regards to subjective burden on the family. Scoring is always on a 3-point scale,

no burden, moderate burden and severe burden. The BIS was standardized in Nigerian by Lasebikan (Lasebikan, 2012). Its split half reliability was 0.849 and the intra-class correlation coefficient for the total score was 0.849 at 95% confidence interval. Test retest reliability of individual scales ranged from 0.780 to 0.874 and for the total objective scale it was 0.830. Its convergent validity was shown by the significant positive correlation (r = 0.83) between the objective burden score and subjective burden score. ROC curve area was 0.981.

3.7.3. The Family Questionnaire (FQ)

The FQ (Appendix II) was developed by Wiedemann, Rayki, Feinstein, and Hahlweg in 2002. It is a 20 item brief self-report questionnaire measuring the EE status (criticism, emotional over-involvement) of relatives of patients with schizophrenia. There are 2 subscales and each subscale consists of 10-item. Items 1, 3, 5, 7, 9, 11, 13, 15, 17, and 19 on FQ measure the construct emotional over involvement. On this subscale (**EOI**), a cut-off of 27 denotes emotional over involvement. Items 2, 4, 6, 8, 10, 12, 14, 16, 18, and 20 on the FQ represent the critical comments (**CC**) subscale. It has a cut-off of 23. Apart from these scores on the FQ, there is also global EE rating. Participants are rated as high EE if their score on at least one of the two subscales was above the cut-off point

The FQ classifications in the initial sample of relatives (N=76) correlated significantly with the ratings in the CFI subcategories 'criticism' (78% correct classifications) and 'emotional over-involvement' (71% correct classifications), as well as with the overall CFI EE ratings (74% correct classifications). A validation study in an independent second sample (N=79) yielded similar results. The overall correct classification rate of 74%

remained unchanged. The FQ had better agreement with the CFI on emotional over-involvement than did other short EE questionnaires.

3.7.4 Multidimensional Scale of Perceived Social Support (MSPSS)

The MSPSS (Appendix V) is a 12 item questionnaire developed by Zimet, Dahlem, Zimet and Farley, in 1988, to measure perceived social support across cultures (Canty-Mitchell and Zimet, 2000; Chou, 2000; Eker, Arkar, and Yaldiz, 2000). The scale was originally developed on university students (Zimet, Dahlem, Zimet, & Farley, 1988) but later it was validated in a wide range of samples, including adolescents, older adults, pregnant women, and psychiatric patients (Kazarian & McCabe, 1991; Stanley, Beck, & Zebb, 1998; Zimet, Powell, Farley, Werkman, & Berkoff, 1990). The MSPSS provides assessment of three sources of support: family (FA), friends (FR), and significant other (SO). Items 1, 2, 5 and 10 are factors grouped as SO; items 3, 4, 8, and 11 are grouped together as FA while items 6, 7, 9 and 12 are summed up as FR. Studies which have used the scale have replicated the 3-factor structure across populations (e.g., Eker et al., 2000; Kazarian & McCabe, 1991; Stanley et al., 1998).

The scale has unique features according to Zimet and colleague (Canty-Mitchell and Zimet, 2000; Zimet et al., 1988). First, it is relatively free of social desirability bias despite its items positive wordings (Dahlem, Zimet, and Walker, 1991; Kazarian and McCabe, 1991). Secondly, it is short (12 items in total) and is ideal for (a) research that requires assessment of multiple variables and (b) populations which, for one reason or another, cannot tolerate a long questionnaire. Thirdly, a point related to (b) above,

MSPSS items are easy to understand (requiring just fourth grade reading level) and are therefore suitable for young populations or populations with limited literacy level.

3.8 Statistical Analysis:

The data was analysed using the Statistical Package for Social Sciences version 21 (SPSS 21). The analysis was based on the total number of respondents. For scales and questions with defined categories, frequencies and percentages were calculated for each of the dimensions of expressed emotion, burden of care, perceived stigma and perceived social support.

The Chi Square and Analysis of Variance (ANOVA) were used to test for the differences and possible associations in the responses between the urban and semi-urban caregivers. Direct logistic regression was used to test for the predictors of high expressed emotion among caregivers while multiple regression analysis was used to test for predictors of burden of care among caregivers. All the tests were two-tailed and the level of significance was set at 0.05. Odds ratio and 95% Confidence Interval were calculated for significant variables.

Chapter Four

Results

4.0 Introduction

This chapter presents the findings of this thesis. The socio-demographic characteristics of the whole cohort of caregivers were presented, as well as the impacts of expressed emotions, burden of care, perceived stigma and perceived social support. The predictors of burden of care and expressed emotion were presented among the cohort. Comparison of socio-demographic characteristics between caregivers in urban and semi-urban settings was presented along with comparisons between them along variables such as expressed emotions, burden of care, perceived stigma and perceived level of social support.

4.1 Socio-demographic characteristics of the whole sample:

The socio-demographic characteristics of the whole cohort are shown in Table 1. The age range of the whole sample was between 15 and 75 years with a mean age of 42 (± 15.6) years and 95% confidence interval of 40 to 45 years. Majority of them are females (57%) and married (49%). A higher proportion of them (68%) came from Yoruba ethnic group while others came from Edo (18%), Igbo (10%), and Hausa (1%). People from minority were 3% (3) in the sample. The predominant family type was monogamy (73%) and religion was Christianity (82%). A higher proportion of the whole sample (53%) had tertiary education while few (6%) had primary school education. Six (6%) of them had no formal education.

About 3 out of ten of the participants indicated that they were sole caregivers for the person with schizophrenia for whom they provide care. Of the people who were carers,

28 (28%) were another member of the family, 23 (23%) sibling, 21 (21%) parent, 14 (14%) children, 11 (11%) spouse and 2 (2%) friend or neighbour. One (1%) other participant reported she was an age concern volunteer. Seventy three (73%) respondents indicated that they lived with the person they cared for and 26 (26%) respondents said the person they cared for lived elsewhere. A further 1 (1%) respondent said she sometimes lived with the person in his care.

Table 1: Socio-demographic characteristics of whole sample and comparison Of these between urban and semi-urban caregivers

Variables	Total	Urban	Semi-urban	Significance
Age				F df p (95% CI)
Mean	42.0 (15.6)	41.0 (15.2)	43.2 (16.1)	0.2 97 0.493 (-8.39to 4.07)
95% CI	38.9-45.2			
Range	15-75			
Gender n (%)				χ df p
				1.02 1 0.313
Female	57 (57)	26 (45.6)	31 (54.4)	
Male	43 (43)	24 (55.8)	19 (44.2)	
Marital Status n (%)				3.453 3 0.327
Single	45 (45)	27 (60)	18 (40)	
Married	49 (49)	20 (40.8)	29 (59.2)	
Separated	4 (4)	2 (50)	2 (50)	
Widow	2 (2)	1 (50)	1 (50)	
Ethnicity				11.448 2 0.003
Yoruba	68 (68)	25 (36.8)	43 (63.2)	
Ibo	10 (10)	6 (60)	4 (40)	
Others	22 (22)	19 (86.4)	3 (13.6)	
Family Type				0.051 1 0.822
Monogamy	73 (73)	37 (50.7)	36 (49.3)	
Polygamy	27 (27)	13 (48.1)	14 (51.9)	
Religion				0.043 1 0.836
Christianity	82 (82)	40 (48.8)	42 (51.2)	
Islam	16 (16)	8 (50)	8 (50)	
Level of education				2.428 2 0.297
Up to Primary	9 (9)	6 (66.7)	3 (33.3)	
Secondary	38 (38)	20 (52.6)	18 (47.4)	
Tertiary	53 (53)	24 (45.3)	29 (54.7)	
Type of caregiving				0.735 1 0.391
Sole caregiving	32 (32)	14 (43.8)	18 (56.3)	
Non-sole	68 (68)	36 (52.9)	32 (47.1)	
Relationship with patient				5.969 4 0.201
Another member	28 (28)	9 (32.1)	19 (67.9)	
Sibling	23 (23)	11 (47.8)	12 (52.2)	
Parent	21 (21)	13 (61.9)	8 (38.1)	
Child	14 (14)	10 (71.4)	4 (28.6)	
Spouse	11 (11)	7 (63.6)	4 (36.4)	
Living with patient				18.407 2 0.000
Yes	73 (73)	46 (63)	27 (37)	
No	26 (26)	4 (15.4)	22 (84.6)	

4.1.1 A comparison of the socio-demographic characteristics of the sample:

The comparison is shown in Table 1. There was no significant difference in a number of factors such as age, sex, marital status, family type, religion, level of education, type of caregiving, and relationship of caregiver to the sick relation. However, there is a significant difference in the two sample populations in terms of ethnicity ($p < 0.001$) and whether or not the caregiver lived with the sick relative ($p < 0.001$).

4.2 Caregivers and the relations

The caregiver characteristics in relation to the sick relation are shown in Table 2. The range of duration of illness in sick relations was 8 to 62 years with a mean of 25.88 (± 8.55) years (95% CI = 23.82 to 27.34). The sick relation has had a mean number of admissions of 1.33 (± 1.25) (95% CI = 1.03 to 1.59). Their median duration of illness since the first hospital admission was 3 (IQR = 4). The caregivers spent an average of 6.86 (± 5.99) minutes of getting to the sick relations. The median number of hours spent per week with a caregiver was 35 (IQR =32) hours. The median duration of time spent caring for the person with schizophrenia was 5 (IQR = 7) hours.

Participants were also asked if the person they cared for had any other mental health or medical conditions other than schizophrenia and 22 (22%) replied in the affirmative. Eight had hypertension, five had diabetes mellitus, three had both diabetes and hypertension, three had asthma, one had sickle cell disease, one had mental retardation and one had depression.

Participants were also asked on a Likert scale if the level of care they offered differed when the person they cared for was hospitalised. Forty two (42%) stated that the level of care was less than usual, 30 (30%) said they provided the same amount of care, and 22 (22%) said that the care they provided increased. Five (5%) stated that the person in their care had never been hospitalized. One respondent did not answer this question.

Of the respondents surveyed, 98 (98%) had participated in paid activities and of these people, 79 (81%) stated that they had to take time off their paid activities because of caring for the sick person in the past one month. The respondents estimated the mean extent that caring had on their paid jobs as 5.4 (± 2.5) on a scale of 0 to 10. As regards unpaid activities, 96 (96%) had participated and of these, 75 (78%) said in the past one month they had to reduce the amount of unpaid work they did due to caring. Likewise, they estimated the mean extent that the caring had on their unpaid activities as 4.6 (± 2.6) on a scale of 0 to 10.

There was no significant difference between the two sample groups in terms of the sick relations' age of onset of illness, the number of hospital admissions, and the duration of illness from the first hospital admission. There was also no significant difference between the two sample groups in the duration of time spent caring for their relation, duration of time spent by caregivers to get to their sick relations and the number of hours per week spent caring for the sick relative. This is shown in Table 2.

Table 2: Caregiver characteristics with sick relations with schizophrenia

Variables		**Urban**	**Semi-urban**	F	df	P (95% CI)
Age of onset of illness						
Mean (S.D)	25.58 (8.55)	25.78 (9.65)	25.20 (7.37)	0.20	97	0.493
95% CI	23.82-27.34					(-8.39 to 4.07)
Median (IQR)	23 (7)					
Range	8-62					
Number of admissions						
Mean (S.D)	1.33 (1.25)	1.44 (1.32)	1.12 (1.15)	3.309	96	0.209
95% CI	1.03-1.59					(-0.18 to 0.81)
Median (IQR)	1 (1.50)					
Range	0-6					
Duration of illness from First admission						
Mean (S.D)	4.73 (5.17)	4.62 (6.02)	4.76 (4.28)	0.006	92	0.9
95% CI	3.66-5.79					(-2.3 to 2.025)
Median (IQR)	3 (4)					
Range	0-37					
Duration of time spent getting to relation						
Mean (S.D)	6.86 (5.99)	7.39 (6.31)	6.88 (6.30)	0.131	98	0.687
95% CI	5.66-8.06					(-1.99 to 3.01)
Median (IQR)	5 (7)					
Range	1-34					
Hours spent caring for Relation						
Mean (S.D)	33.51 (21.80)	35.55 (24.47)	31.24 (18.67)	0.06	97	0.328
95% CI	29.14-37.88					(-4.39 to 13.0)
Median (IQR)	35 (22)					
Range	1-133					
Duration of time of care						
Mean (S.D)	7.14 (6.28)	7.39 (6.31)	6.88 (6.30)	0.131	98	0.687
95% CI	5.89-8.38					(-1.99 to 3.01)
Median (IQR)	5 (7)					
Range	1-34					

4.3 The expressed emotion in the whole sample and comparison in urban and semi-urban settings:

The expressed emotion of the whole sample is shown in Table 3. Thirty three (33%) of the whole sampled population had high expressed emotions. Twenty one (21%) of the participating caregivers had high emotional over-involvement with a median of 19 (IQR 9.0) while 17 (17%) of them had high critical comments about their sick relation and a median score of 15.0 (IQR 8.0). In this study, the expressed emotions components were tested separately because they are theoretically distinct according to Scazufca and Kuipers (1996).

4.3.1 Impact of Components of Expressed emotion on socio-demographic characteristic of caregivers:

The mean scores of Critical Comments (CC) and Emotional Over-involvement (EOI) were disaggregated by subjects' socio-demographic characteristics including demographic subgroupings.

For CC, there was no significant gender difference in the mean scores ($t = -0.782$, $df = 98$, $p = 0.433$). While for EOI, there was also no significant gender difference in the mean scores ($t = 0.221$, $df = 98$, $p = 0.826$).

A one-way between-groups analysis of variance was conducted to explore the impact of Critical comments (CC) and Emotional over-involvement (EOI) on levels of age of carers, occupation, religion, relationship of carers to patient, illness duration and education of carers. This is shown in Tables 3a and 3b.

With regards to CC, the only significant difference was in the level of education. As regards the level of education in relation to CC, the participants were divided into 4 groups (Group 1 (n=6): no formal education; Group 2 (n=3): primary education; Group 3 (n=38): secondary; Group 4 (n=50): tertiary education). There was a statistically significant difference at the $p < 0.01$ level in the CC scores for the 4 groups: $F(3, 96) = 3.126$, $p = 0.029$. The actual difference in mean scores between the groups was medium. The effect size, calculated using eta squared, was 0.09. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for group 2 ($M = 5.33$, $SD = 4.62$) was significantly different from Group 3 ($M = 17.00$, $SD = 9.03$). There was no other significant difference from between other groups.

With regards to EOI, the only significant difference was found in the relationship of carer to patients. With regards to EOI for relationship of carers to patients, the participants were divided into 5 groups [Group 1: spouse (n=11); Group 2: children (n=14); Group 3: sibling (n=23); Group 4: another member of family (n=28) and Group 5: parent (n=21)]. There was a statistically significant difference at the $p < 0.01$ level in the EOI scores for the 5 groups: $F(4, 97) = 2.289$, $p = 0.042$. The actual difference in mean scores between the groups was large. The effect size, calculated using eta squared, was 0.13. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for group 3 ($M = 16.04$, $SD = 4.89$) was significantly different from Groups 1 ($M = 20.09$, $SD = 3.88$), Group 2 ($M = 22.36$, $SD = 8.60$), Group 4 ($M = 22.39$, $SD = 8.90$) and Group 5 ($M = 21.95$, $SD = 6.04$).

Table 3a: One way Analysis of variance showing relationships between Critical Comments and socio-demographic characteristics of the caregivers

Variables	N	Mean (SD)	df	F	P
Age			95	0.520	0.721
15-20	3	13.33			
21-30	21	(11.72)			
31-40	22	14.62 (4.90)			
41-50	21	16.77			
>50	33	(11.68)			
		6.66 (1.45)			
		5.67 (0.99)			
Occupation			85	0.683	0.751
Professional	16	15.29 (6.40)			
Technician	10	15.43 (4.04)			
Salesperson	23	16.58			
Crafts	8	(11.60)			
Elementary	9	15.00 (4.99)			
Retired	13	15.00 (4.72)			
Student	13	15.54 (4.72)			
		13.85 (5.71)			
Religion			97	1.096	0.338
Eckankar	2	10.05 (3.54)			
Christianity	82	15.50 (7.64)			
Islam	16	13.13 (7.27)			
Duration of illness			95	0.152	0.928
≤ 2	32	14.31			
3-5	30	(10.66)			
6-10	24	15.27 (5.11)			
>10	13	15.63 (6.23)			
		15.02 (7.55)			
Relationship to patient			97	0.958	0.458
Spouse	11	14.73 (6.08)			
Children	14	10.79 (6.73)			
Sibling	23	15.87			
Another family	28	(11.57)			
member	21	16.25 (4.77)			
Parent		15.81 (6.29)			
Level of education			96	3.126	0.029*
None	6	11.67 (3.44)			
Primary	3	5.33 (4.62)			
Secondary	38	17.00 (9.03)			
Tertiary	53	14.68 (6.25)			

*$p<0.05$

Table 3b: One way Analysis of variance showing relationships between Emotional Overinvolvement and socio-demographic characteristics of the caregivers

Variables	N	Mean (SD)	df	F	P
Age			95	0.722	0.579
15-20	3	18.00 (4.36)			
21-30	21	19.86 (4.88)			
31-40	22	22.54			
41-50	21	(11.96)			
>50	33	19.24 (5.37)			
		20.45 (5.39)			
Occupation			85	0.617	0.810
Professional	16	19.82 (8.59)			
Technician	10	19.71 (4.46)			
Salesperson	23	21.67 (4.78)			
Crafts	8	21.00 (3.97)			
Elementary	9	21.33 (5.86)			
Retired	13	19.69 (6.18)			
Student	13	21.69 (9.56)			
Religion			97	0.121	0.886
Eckankar	2	22.50 (6.36)			
Christianity	82	20.51 (7.67)			
Islam	16	19.93 (4.85)			
Duration of illness			95	0.707	0.550
≤ 2	32	21.63 (8.35)			
3-5	30	19.33 (5.03)			
6-10	24	20.83 (9.00)			
>10	13	21.00 (4.90)			
Relationship to patient			97	2.289	0.042*
Spouse	11	20.09 (3.88)			
Children	14	22.36 (8.60)			
Sibling	23	16.04 (4.89)			
Another family member	28	22.39 (8.90)			
Parent	21	21.95 (6.05)			
Level of education			96	0.256	0.857
None	6	21.00 (5.06)			
Primary	3	21.67 (3.06)			
Secondary	38	19.66 (7.57)			
Tertiary	53	20.91 (7.42)			

*$p<0.05$

4.3.2 Comparison of Expressed emotion and its components in urban and semi-urban settings:

The two populations sampled were compared on their level of global expressed emotions and also by the components of emotional over-involvement as well as critical comments. This is also shown in Table 4. The urban sample had significantly different higher

proportion of global expressed emotion than the semi-urban sample ($\chi^2 = 10.176$, df = 1; p = 0.003). The odds of a carer who lives in an urban setting exhibiting high expressed emotion is 4.202 times higher than the odds of carer who lives in a semi-urban setting (95% CI = 1.692 to 10.42). The urban sample also had significantly higher proportion of caregivers with emotional over-involvement compared with the semi-urban sample ($\chi^2 = 7.294$, df = 1; p = 0.013). The odds of a carer who lives in an urban setting exhibiting emotional over-involvement is 4.237 times higher than the odds of a carer who lives in a semi-urban setting (95% CI = 1.412 to 12.66). The result of comparison on critical comments was also significantly different between the two groups with Lagos sample of caregivers having higher proportion ($\chi^2 = 5.741$, df = 1; p = 0.031). The odds of a carer who lives in an urban setting exhibiting critical comments is 4.049 times higher than the odds of a carer who lives in semi-urban setting (95% CI = 1.215 to 13.51).The median values of emotional over-involvement and critical comments of the two groups were also compared and the Lagos sample had significantly higher value (MW= x, p = 0.001; and MW = 929.5, p = 0.027 respectively). This significance held when the variables of ethnicity and living with the sick relation or not were controlled for.

4.3.3 Predictors of High Expressed Emotions among Caregivers:

Direct logistic regression was performed to assess the impact of a number of factors on the likelihood that respondents would report having high expressed emotions (Table 5). The model contained 15 independent variables (age, gender, social support, religion, onset age in sick person, number of admissions, duration of illness in sick person, subjective burden, objective burden, relationship with patient, duration of care, living with the patient, hours spent per week with person sick, devaluation, and discrimination).

The full model containing all predictors was statistically significant Chi (22, N = 85) = 28.624, p = 0.0156, indicating that the model was able to distinguish between respondents who have high expressed emotions and those who do not. The model as a whole explained between 28.6% (Cox and Snell R square) and 40.1% (Nagelkerke R squared) of the variance in expressed emotions and correctly classified 82.4% of cases.

As shown in Table 4, only seven of the independent variables made a unique statistically significant contribution to the model (age of carer, perceived social support, age of onset of illness in sick relative, relationship to the person with schizophrenia, duration of caring for the person with schizophrenia, living with patient with schizophrenia and objective burden).

The strongest predictor is relationship with person with schizophrenia recording an odds ratio of 75.218. This indicated that the respondents who were friends/neighbours were 75 times more likely to report high expressed emotions than a spouse controlling for other factors. The odds of a person having high expressed emotions is 9.434 times higher for a person living with a person being cared for than those who do not stay with the person being cared for. The more support a carer has, the less likely s/he is to have high expressed emotions. For every extra support this person gets, the odds of him/her having high expressed emotions is reduced by a factor of 0.162 all factors being equal. The older a carer gets, the less likely s/he is to have high expressed emotions, and for extra one year a carer adds, the odds of him/her having high expressed emotion is reduced by a factor of 0.931 all factors being equal.

Table 4: Expressed emotions and components for the whole sample and disaggregated by centres

Variable	Total	**Urban**	**Semi-urban**	Statistic	df	Signi Ficance	OR (95% CI)
Global EE							4.202 (1.692-10.42)
Present	33 (33)	24 (72.7)	9 (27.3)	10.176	1	0.003	
Absent	67 (67)	26 (38.8)	41 (61.2)				
EOI							4.237 (1.412-12.66)
Present	21 (21)	16 (76.2)	5 (23.8)	7.294	1	0.013	
Absent	79 (79)	34 (43.0)	45 (57.0)				
Median (IQR)	19.00 (9.00)	60.15	40.85			0.001	
CC							4.049 (1.215-13.51)
Present	17 (17)	13 (76.5)	4 (23.5)	5.741	1	0.031	
Absent	83 (83)	37 (44.6)	46 (55.4)				
Median (IQR)	15.00 (8.00)	44.09	56.91	929.5		0.027	

Table 5: Binary Logistic Regression predicting Likelihood of Expressed Emotions in Study Cohort

Variables	B	S.E	Wald	df	P	Odds ratio	95% Confidence Interval
Age	-0.072	0.034	4.478	1	0.034	0.931	0.871 to 0.995
Sex	-0.672	0.768	0.767	1	0.381	0.510	0.113 to 2.298
Perceived social support	-1.818	0.970	3.517	1	0.05	0.162	0.024 to 1.086
Religion	2.682	2.823	0.902	1	0.342	14.615	0.058 to 3698
Illness onset age	0.095	0.047	4.136	1	0.042	1.099	1.003 to 1.204
Number of admissions	0.130	0.277	0.221	1	0.638	1.139	0.662 to 1.962
Subjective burden	-1.010	1.407	0.515	1	0.473	0.364	0.023 to 5.744
Relationship to sick person	4.32	1.690	0.538	1	0.011	75.218	2.742 to 2063
Duration of care	0.130	0.063	4.199	1	0.04	1.139	1.006 to 1.289
Living with sick person	2.244	1.101	4.155	1	0.042	9.434	1.09 to 81.64
Hours spent with person	-0.009	0.018	0.230	1	0.631	0.991	0.957 to 1.027
Devaluation	-0.116	0.960	0.015	1	0.904	0.890	0.136 to 5.839
Objective burden	0.094	0.051	3.435	1	0.05	1.099	0.995 to 1.214
Constant	-7.713	4.596	2.816	1	0.093	0.000	

4.4 The burden of care of the whole sample and of caregivers in urban and semi-urban settings:

The burden of care of the caregivers in the whole sample was explored and this is shown in Table 6. The overall objective burden score was obtained from adding the rating for each of the 24 items on the Burden Interview Scale. The mean objective burden for the respondents in this cohort was 20.10 (± 8.45) and the range was 2 to 45. The mean overall financial burden was highest 5.77 (± 2.34) with 95% confidence interval of 5.26 to 6.29 and this was followed by the mean overall family activity disrupted which was 4.31 (± 2.18) with 95% confidence interval of 3.87 to 4.74. The overall effect on physical health had the least burden with a mean of 1.15 (± 1.09) and a 95% confidence interval of 0.93 to 1.37.

With regards to the subjective burden in the whole cohort, 9 (9%) stated they had no burden, 32 (32%) had a little burden while majority (59%) had severe burden.

4.4.1 Impact of FBIS on socio-demographic characteristics of caregivers:

The mean scores of FBIS were disaggregated by subjects' socio-demographic characteristics including demographic subgroupings. There was no significant gender difference in the mean scores with mean difference of 0.686 ($t = 0.394$, $df = 95$, $p = 0.694$).

A one-way between-groups analysis of variance was conducted to explore the impact of burden of care (FBIS) on levels of age of carers, occupation, religion, relationship of carers to patient, illness duration and education of carers. This is shown in Table 7. The

only significant relationship was found at the level of the relationship of carers to patients.

For relationship of carers to patients, the participants were divided into 5 groups [Group 1: spouse (n=9); Group 2: children (n=14); Group 3: sibling (n=23); Group 4: another member of family (n=28) and Group 5: parent (n=21)]. There was a statistically significant difference at the $p < 0.01$ level in the FBIS scores for the 5 groups: $F(4, 95) = 3.181$, $p = 0.007$. The actual difference in mean scores between the groups was large. The effect size, calculated using eta squared, was 0.17. Post-hoc comparisons using the Tukey HSD test indicated that the mean score for group 1 ($M = 23.56$, $SD = 9.84$) was significantly different from Groups 2 ($M = 16.07$, $SD = 7.60$), Group 3 ($M = 17.23$, $SD = 9.32$) and Group 5 ($M = 18.71$, $SD = 6.00$). The mean score for Group 4 ($M = 24.18$, $SD = 7.42$) was also significantly different from Groups 2 ($M = 16.07$, $SD = 7.60$), Group 3 ($M = 17.23$, $SD = 9.32$) and Group 5 ($M = 18.71$, $SD = 6.00$). Groups 2, 3 and 5 did not differ significantly from each other.

4.4.2 Predictors of burden among carers:

Multiple regression analysis was used to assess the predictors of objective burden in the sample. The possible predictors included were relationship of carer to person with schizophrenia, number of admissions, living with person with schizophrenia, level of care when person with schizophrenia hospitalized, age of onset of illness in person with schizophrenia, duration of illness from first admission, perceived level of social support, perceived stigma, level of discrimination, and level of devaluation. Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity,

multicollinearity, and homoscedasticity. The model (F= 2.672, df = 10, p = 0.006) explained 17% of the variance in objective burden. In the model, perceived level of social support was the largest contributor (beta = -0.302, p = 0.006) when other variables were controlled for. Apart from this variable, other variables that were significant were living with the person with schizophrenia (beta = -0.228, p = 0.035), number of admissions (beta = 0.237, p = 0.032), and discrimination (beta = -0.245, p = 0.027).

The carer who lives with a relation with schizophrenia has the odds of 4.386 times to have objective burden compared with a carer who did not live with a relation with schizophrenia (p = 0.035; 95% CI = -8.096 to -0.305). The number of admissions is positively correlated with objective burden. The higher the number of admissions in hospital of a person with schizophrenia, the odds of this carer having objective burden is 4.219 times the odds of a carer of a person with schizophrenia who had no admissions (p = 0.032; 95% CI = 0.141 to 3.080). The perceived discrimination is negatively correlated with objective burden. When a carer has perceived discrimination the odds of this person having objective burden is 4.082 times the odds of a carer who did not have perceived discrimination (p = 0.027; 95% CI = -7.730 to -0.467). A carer without perceived social support has 3.311 odds of having objective burden than a carer of a person with schizophrenia who has perceived social support (p = 0.006; 95% CI = -6.105 to -1.082).

With regards to subjective burden, in the urban sample, 2 (4%) had no burden, 17 (34%) had little burden and 31 (62%) had severe burden. In the semi-urban sample, 7 (14%) had no burden, while 15 (30%) had little burden and 28 (56%) had severe burden.

Comparison of these samples did not show any significant difference ($\chi^2 = 3.055$, df =2, p = 0.217)

4.4.3 Comparison of burden of care in Urban and Semi-urban caregivers:

The urban sample and the semi-urban sample were compared along the parameters of burden of care. This is shown in Table 6. The overall objective burden for urban area was 22.75 (± 8.50) while for semi-urban area it was 17.51 (± 7.62). There was a significant difference (F = 0.921, df = 95, p = 0.002, 95% confidence interval of -8.49 to -1.99). The caregivers who lived in urban area had significantly higher mean values in the areas of overall financial burden, disruptions of family leisure and family interactions. They also had significantly higher proportion of any other burdens than those living in semi-urban area ($\chi^2 = 5.482$, df =1, p = 0.034).

Table 6: Dimensions of burden of care disaggregated by the whole sample and two sample populations

Variables	Total	**Semi-urban**	**Urban**	Stat	Df	P	95% CI
Overall financial Burden Mean (S.D) 95% CI	 5.77 (2.34) 5.26-6.29	 5.12 (2.34)	 6.50 (2.73)	 0.613	 98	 0.008	 -2.39 to -0.37
Overall Family Activities Disruption Mean (S.D) 95% CI	 4.31 (2.18) 3.87-4.74	 4.04 (2.08)	 4.68 (2.30)	 1.030	 98	 0.148	 -1.51 to 0.23
Overall Family Leisure Disruption Mean (S.D) 95% CI	 3.56 (2.00) 3.15-3.96	 2.82 (1.97)	 4.37 (1.81)	 0.726	 97	 0.000	 -2.30 to -0.79
Overall Family Interaction Disruption Mean (S.D) 95% CI	 3.90 (2.40) 3.41-4.38	 3.22 (2.25)	 4.58 (2.39)	 0.440	 95	 0.005	 -2.29 to -0.42
Overall effect on Physical health Mean 95% CI	 1.15 (1.09) 0.93-1.37	 1.04 (1.12)	 1.28 (1.07)	 0.035	 98	 0.277	 -0.68 to 0.20
Overall effect on Mental health Mean 95% CI	 1.41 (1.13) 1.19-1.64	 1.28 (0.90)	 1.60 (1.29)	 9.646	 98	 0.155	 -0.76 to 0.12
Any other burden n (%) Yes No	 24 (24) 76 (76)	 6 (25) 44 (57.9)	 18 (75) 32 (42.1)	 5.482	 1	 0.034	
Overall Physical Health n (%) Yes No	 60 (60) 40 (40)	 27 (45) 17 (42.5)	 33 (55) 23 (57.5)	 1.500	 1	 0.307	
Overall Mental Health n (%) Yes No	 78 (78) 22 (22)	 37 (47.4) 9 (40.9)	 41 (52.6) 13 (59.1)	 0.932	 1	 0.470	

Table 7: One way Analysis of variance showing relationships between burden of care and socio-demographic characteristics of the caregivers

Variables	N	Mean (SD)	df	F	P
Age			92	0.308	0.872
15-20	3	20.33 (5.03)			
21-30	21	21.81 (6.82)			
31-40	20	20.10 (11.96)			
41-50	21	19.76 (8.15)			
>50	32	19.19 (7.48)			
Occupation			85	1.194	0.307
Professional	16	18.94 (9.62)			
Technician	10	25.71 (6.52)			
Salesperson	23	23.00 (8.12)			
Crafts	8	15.52 (14.03)			
Elementary	9	14.66 (6.50)			
Retired	13	21.92 (6.68)			
Student	13	19.23 (8.51)			
Religion			94	0.325	0.723
Eckankar	2	22.00 (9.90)			
Christianity	79	19.77 (8.85)			
Islam	16	21.50 (6.35)			
Duration of illness			92	0.257	0.856
≤ 2	31	19.71 (8.85)			
3-5	28	20.07 (6.66)			
6-10	24	21.25 (9.77)			
>10	13	20.08 (8.49)			
Relationship to patient			95	3.181	0.007*
Spouse	9	23.56 (9.84)			
Children	14	16.07 (7.66)			
Sibling	23	17.22 (9.32)			
Another family member	28	24.17 (7.42)			
Parent	21	18.71 (6.00)			
Level of education			93	0.803	0.495
None	6	15.50 (7.66)			
Primary	3	18.33 (3.51)			
Secondary	38	21.08 (7.59)			
Tertiary	50	20.02 (9.29)			

*p<0.05

4.4.4 Comparison of dimensions of burden of care along the global expressed emotion, emotional over-involvement and critical comments within whole sample and within urban and semi-urban centres

For the total objective burden, there was no significant difference between those with high expressed emotion (19.17±8.52) compared with those with low expressed emotion (22.00±8.10) [F = 1.676, df = 95, p = 0.12, 95% confidence interval of -6.43 to 0.77]. Among those with high (22.20±8.50) and low (19.56±8.41) Emotional over-involvement,

there was no significant difference [F=1.027, df = 95, p = 0.22, 95% confidence interval of -6.84 to 1.56]. Among those with high critical (22.65±8.80) and low (19.56±8.33) critical comments, there was also no significant difference [F = 0.137, df = 95, p = 0.17, 95% confidence interval of -7.54 to 1.38].

However, when the relationship between critical comments and objective burden was investigated using Pearson product-moment correlation coefficient, there was a medium positive correlation between the two variables, r = 0.39, n = 97, p < 0.001 with high levels of objective burden associated with high levels of critical comments. Objective burden helps to explain 15% of the variance in respondents' scores on critical comments. There was no significant correlation between emotional over-involvement and objective burden (r = 0.19, n = 97, p = 0.06).

The relationships between subjective burden and critical comments and emotional over-involvement were investigated, but there was only a significant measure of association between critical comments and subjective burden ($\chi^2 = 7.554$, df =2, p = 0.023) with high levels of subjective burden associated with high levels of critical comments. For emotional over-involvement, $\chi^2 = 0.893$, df =2, p = 0.64.

The whole sample was divided into two groups of high and low burden of care each using the dimensions of overall financial burden, family activity disruption, family leisure disruption, family interaction disruption, overall effect on physical health and overall effect on mental health and were compared if they were different in terms of global

expressed emotion, emotional over-involvement and critical comments. This is shown in Table 8.

There was a significant difference in the whole sample on critical comments between those who had high overall financial burden compared with low overall financial burden. Those with high overall financial burden had significantly higher mean score on critical comments (F = 0.065, df = 98, p = 0.02, 95% CI = -6.27 to -0.56).

With regards to disruption in family activity, those with high burden had significantly higher mean score in critical comments (F = 0.016, df = 98, p = 0.032, 95% CI = -6.12 to 0.29). In the family leisure dimension too, those with high burden had significantly higher critical comments compared with those with low burden (F = 0.999, df = 98, p = 0.016, 95% CI = -6.48 to -0.67). This is the case in family interaction dimension (F = 0.000, df = 98, p = 0.008, 95% CI = -7.55 to -1.20); in overall effect on physical health F = 0.506, df = 98, p = 0.015, 95% CI = -6.84 to -0.76); and overall effect on mental health F = 0.032, df = 98, p = 0.006, 95% CI = -7.36 to -1.29).

Within each sample, two groups were created using burden of care. These two groups were compared if they were different in terms of global expressed emotion, emotional over-involvement and critical comments. There was no significant difference in each of the urban or semi-urban areas in the dimensions of overall financial burden, overall family activity disruption and overall effect on physical health.

However, in the semi-urban centre, there were significant differences with those with high burden having higher mean score on critical comments in the following areas: family leisure disruption (F = 0.005, df = 48, p = 0.005, 95% CI = -9.66 to -1.89); and family interaction disruption (F = 0.935, df = 48, p = 0.016, 95% CI = -9.15 to -0.99).

The urban centre had a significant difference in mean score on critical comments in the dimension of overall effect on mental health (F = 0.05, df = 48, p = 0.014, 95% CI = -8.96 to -1.06).

Table 8: Burden of care disaggregated by whole sample and urban/semi-urban areas along components of Expressed Emotion

Variables	Low Burden	High Burden	Statistics	df	p	95% CI
Overall financial Burden						
Cohort						
Present EE	14 (42.4)	19 (57.6)	0.004	1	0.952	
Absent EE	28 (41.8)	39 (58.2)				
Urban						
Present EE	11 (45.8)	13 (54.2)	1.239	1	0.266	
Absent EE	16 (61.5)	10 (38.5)				
Semi-urban						
Present EE	3 (33.3)	6 (66.7)	0.058	1	0.810	
Absent EE	12 (29.3)	29 (70.7)				
Cohort						
EOI	20.14 (7.05)	20.69 (7.41)	0.111	98	0.709	-3.45 to2.35
CC	13.12 (6.25)	16.54 (8.13)	0.065	98	0.020	-6.27to -0.56
Urban						
EOI	21.70 (7.57)	24.48 (5.22)	0.646	48	0.672	-4.44 to 2.89
CC	12.48 (6.68)	15.09 (7.12)	0.080	48	0.196	-6.60to 1.39
Semi-urban						
EOI	17.33 (5.09)	19.51 (8.41)	0.079	48	0.267	-8.06to 1.62
CC	14.27 (4.99)	17.49 (8.70)	0.008	48	0.107	-7.16 to 0.72
Overall Family Activities Disruption						
Cohort						
Present EE	8 (24.2)	25 (75.8)	0.777	1	0.378	
Absent EE	22 (32.8)	45 (67.2)				
Urban						
Present EE	6 (25)	18 (75)	2.424	1	0.119	
Absent EE	12 (46.2)	14 (53.8)				
Semi-urban						
Present EE	2 (22.2)	7 (77.8)	0.019	1	0.890	
Absent EE	10 (24.4)	31 (75.6)				
Cohort						
EOI	19.57 (5.64)	20.84 (7.82)	0.727	98	0.362	-4.05 to 1.49
CC	12.83 (6.23)	16.07 (7.91)	0.016	98	0.032	-6.12 to 0.29
Urban						
EOI	21.56 (5.51)	22.34 (7.13)	1.164	48	0.665	-4.44 to 2.86
CC	11.72 (6.79)	14.78 (7.03)	0.178	48	0.140	-7.17 to 1.05
Semi-urban						
EOI	16.58 (4.56)	19.58 (8.24)	0.400	48	0.119	-6.81 to 0.81
CC	14.50 (5.09)	17.16 (8.52)	0.015	48	0.197	-6.77 to 1.45
Overall Family Leisure Disruption						
Cohort						
Present EE	17 (51.5)	16 (48.5)	1.831	1	0.176	
Absent EE	25 (37.3)	42 (62.7)				
Urban						
Present EE	16 (66.7)	8 (33.3)	0.142	1	0.706	
Absent EE	16 (61.5)	10 (38.5)				
Semi-urban						
Present EE	1 (11.1)	8 (88.9)	0.542	1	0.462	
Absent EE	9 (22)	32 (78)				

Table 8: Burden of care disaggregated by whole sample and urban/semi-urban areas along components of Expressed Emotion

Variable	Low Burden	High Burden	Stat	df	P	95% CI
Overall Family Leisure Disruption						
Cohort						
EOI	21.38 (6.98)	19.79 (7.39)	0.267	98	0.277	-1.29 to 4.47
CC	13.02 (6.78)	16.60 (7.79)	0.999	98	0.016	-6.48 to -0.67
Urban						
EOI	22.65 (7.06)	21.00 (5.54)	0.152	48	0.365	-1.99 to 5.30
CC	13.38 (7.39)	14.22 (6.51)	0.603	48	0.677	-4.92 to 3.23
Semi-urban						
EOI	17.30 (5.10)	19.25 (8.09)	0.162	48	0.354	-6.22 to 2.32
CC	11.90 (4.38)	17.68 (8.15)	0.005	48	0.005	-9.66 to -1.89

4.5 The perceived stigma of the caregivers:

The perceived stigma among the caregivers was measured with perceived devaluation-discrimination scale with a total score range of 1 to 6 with higher scores signifying higher perceived stigma. The scores are further categorised into 0 to 1 representing low, 2 to 4 representing moderate and 5 to 6 representing high perceived stigma. This is shown in Table 9a.

In the whole sample, the perceived stigma was moderate with a mean of 2.77 (± 0.56) while the level of perceived devaluation among the caregivers was moderate with a mean of 2.74 (± 1.05) and the level of perceived discrimination among them was also moderate with a mean of 2.79 (± 0.51).

In order to create categories of caregivers along the dimensions of perceived stigma and its component, the percentile distribution of the scores was explored. For perceived stigma, score less than 2.1 was categorised as low stigma, 2.2 to 3.1 as moderate and

above 3.2 as high stigma. For discrimination, and devaluation, less than 2.2 was categorised as low, 2.3 to 3.0 as moderate and above 3.1 as high.

The frequency distribution in the perceived stigma revealed that for the whole cohort, majority had moderate perceived stigma [n=64 (75.3%)], while 11 (12.9%) had high perceived stigma and 10 (11.8%) had low perceived stigma. For discrimination, 52 (52%) had moderate perceived discrimination, 29 (29%) had high discrimination and 13 (13%) had low discrimination. For the devaluation component, 48 (48%) had moderate, followed by 27 (27%) with low devaluation and 24 (24%) with high devaluation.

Comparison of these perceived stigma, discrimination and devaluation is shown in Table 9b.

In perceived stigma, there was almost a significant difference between the urban and semi-urban samples at level of $p = 0.051$, where the odds of caregivers living in urban having moderate stigma is 2.3 times the odds of caregiver living in semi-urban ($z = 1.154$, 95% CI = 0.5536 to 9.834, $p = 0.2483$); and the odds of caregivers living in urban having high stigma is 10.5 times the odds of caregiver living in semi-urban ($z = 2.255$, 95% CI = 1.360 to 81.06, $p = 0.0241$). However, exploration of this difference using PDDS continuous scores did not show any significant variation (rf. Table 9a).

There is a significant difference in between the caregivers living in urban and semi-urban settings when it concerns perceived discrimination. The odds of a caregiver living in urban having moderate discrimination is 5.5 times the odds of caregiver living in semi-

urban (z = 2.086, 95% CI = 1.109 to 27.29, p = 0.037) and the odds of caregivers living in urban having high discrimination is 7.79 times the odds of caregiver living in semi-urban (z = 2.398, 95% CI = 1.455 to 41.73, p = 0.017). This significant difference persisted when discrimination continuous variable was compared between the urban and semi-urban samples (rf. Table 9a)

There was no significant difference between the urban and semi-urban caregivers along the devaluation dimension. The exploration of this difference using devaluation continuous scores did not also show any significant variation (rf. Table 9a).

Table 9a: The level of stigma and components disaggregated by whole sample and urban/semi-urban groups

Variable	Total	Urban	Semi-urban	statistic	df	significance	95% CI
PDDS total							
Median (IQR)	2.83 (0.67)	55.25	44.64	962.5		0.065	
Mean (S.D)	2.77 (0.56)	2.83 (0.41)	2.71 (0.69)	1.271	97	0.313	-0.11 to 0.34
Devaluation							
Median (IQR)	2.80 (0.80)	51.52	48.45	1149		0.592	
Mean (S.D)	2.74 (1.05)	2.70 (0.55)	2.79 (1.39)	2.060	97	0.683	-0.52 to 0.34
Discrimination							
Median (IQR)	2.86 (0.57)	56.88	44.12	931.0		0.027	
Mean (S.D)	2.79 (0.51)	2.92 (0.45)	2.66 (0.53)	0.642	98	0.010	0.06 to 0.45

Table 9b: The level of stigma and components disaggregated by whole sample and urban/semi-urban group

	Whole Sample	Urban	Semi-Urban	Statistics
PDDS n (%)				χ^2 =5.956, df = 2, p 0.051
Low	10 (11.8)	3 (30)	7 (70)	
Moderate	64 (75.3)	32 (50)	32 (50)	
High	11 (12.9)	9 (81.8)	2 (18.2)	
Discrimination n (%)				χ^2 =6.935, df = 2, p 0.031
Low	13 (13)	2 (15.4)	11 (84.6)	
Moderate	52 (52)	26 (50)	26 (50)	
High	29 (29)	17 (58.6)	12 (41.4)	
Devaluation n (%)				χ^2 =5.472, df = 2, p 0.065
Low	27 (27)	10 (37)	17 (63)	
Moderate	48 (48)	30 (62.5)	18 (37.5)	
High	24 (24)	10 (41.7)	14 (58.3)	

4.5.1 Impact of Perceived Stigma, discrimination and devaluation on socio-demographic characteristics of carers:

The mean scores of PDDS were disaggregated by subjects' socio-demographic characteristics including demographic subgroupings. There was no significant gender difference in the mean scores ($t = -1.003$, $df = 97$, $p = 0.318$). For discrimination scores, there was no significant gender difference in the mean scores ($t = -0.044$, $df = 98$, $p = 0.965$). For devaluation scores, there was no significant gender difference in the mean scores ($t = -1.275$, $df = 97$, $p = 0.206$).

A one-way between-groups analysis of variance was conducted to explore the impact of stigma (PDDS) and its components (discrimination and devaluation) on levels of age of carers, occupation, religion, relationship of carers to patient, illness duration and education of carers. There was no significance relationship found between PDDS and its components on all the levels of the variables included. This is shown in Tables 10 a, b and c.

Table 10a: One way Analysis of variance showing relationships between PDDS and socio-demographic characteristics of the caregivers

Variables	N	Mean (SD)	df	F	P
Age			91	1.000	0.412
15-20	3	3.11 (0.25)			
21-30	21	2.64 (0.39)			
31-40	22	2.64 (0.47)			
41-50	20	2.84 (0.27)			
>50	32	2.87 (0.80)			
Occupation			85	0.590	0.832
Professional	17	2.88 (1.05)			
Technician	7	2.76 (0.20)			
Salesperson	23	2.85 (0.45)			
Crafts	7	2.91 (0.25)			
Elementary	5	2.86 (0.47)			
Retired	13	2.69 (0.52)			
Student	13	2.65 (0.37)			
Religion			96	0.746	0.477
Eckankar	3	3.25 (0.12)			
Christianity	82	2.77 (0.60)			
Islam	15	2.74 (0.36)			
Duration of illness			94	0.451	0.717
≤ 2	32	2.72 (0.43)			
3-5	29	2.87 (0.77)			
6-10	24	2.73 (0.50)			
>10	13	2.71 (0.44)			
Relationship to patient			96	0.921	0.484
Spouse	11	3.12 (1.13)			
Children	14	2.70 (0.43)			
Sibling	23	2.67 (0.42)			
Another family member	27	2.73 (0.44)			
Parent	21	2.79 (0.51)			
Level of education			95	0.866	0.462
None	6	2.61 (0.57)			
Primary	3	3.06 (0.55)			
Secondary	37	2.69 (0.39)			
Tertiary	53	2.83 (0.66)			

Table 10b: One way Analysis of variance showing relationships between Discrimination and socio-demographic characteristics of the caregivers

Variables	N	Mean (SD)	df	F	P
Age			95	3.142	0.108
15-20	3	3.33 (0.22)			
21-30	21	2.64 (0.56)			
31-40	22	2.59 (0.53)			
41-50	21	2.94 (0.24)			
>50	33	2.88 (0.53)			
Occupation			95	1.293	0.242
Professional	17	2.66 (0.60)			
Technician	7	2.71 (0.35)			
Salesperson	24	2.94 (0.49)			
Crafts	11	2.32 (0.34)			
Elementary	10	3.14 (0.52)			
Retired	13	2.75 (0.55)			
Student	13	2.82 (0.50)			
Religion			97	1.012	0.367
Eckankar	3	3.29 (0.40)			
Christianity	82	2.79 (0.50)			
Islam	16	2.75 (0.53)			
Duration of illness			95	0.449	0.719
≤ 2	32	2.75 (0.52)			
3-5	30	2.78 (0.44)			
6-10	24	2.77 (0.55)			
>10	13	2.93 (0.54)			
Relationship to patient			96	1.095	0.371
Spouse	11	2.81 (0.54)			
Children	14	2.96 (0.40)			
Sibling	23	2.63 (0.49)			
Another family member	28	2.72 (0.57)			
Parent	21	2.91 (0.47)			
Level of education			96	1.359	0.260
None	6	2.79 (0.60)			
Primary	3	3.29 (0.62)			
Secondary	38	2.71 (0.49)			
Tertiary	53	2.82 (0.50)			

Table 10c: One way Analysis of variance showing relationships between Devaluation and socio-demographic characteristics of the caregivers

Variables	N	Mean (SD)	df	F	P
Age			95	0.184	0.946
15-20	3	2.80 (0.53)			
21-30	21	2.64 (0.61)			
31-40	22	2.70 (0.53)			
41-50	21	2.69 (0.61)			
>50	33	2.87 (1.65)			
Occupation			94	0.528	0.879
Professional	17	3.18 (2.20)			
Technician	7	2.83 (0.31)			
Salesperson	23	2.70 (0.56)			
Crafts	11	2.80 (0.33)			
Elementary	10	2.47 (0.42)			
Retired	13	2.60 (0.71)			
Student	13	2.40 (0.69)			
Religion			96	0.189	0.828
Eckankar	3	3.20 (0.28)			
Christianity	82	2.73 (1.13)			
Islam	15	2.73 (0.54)			
Duration of illness			94	1.130	0.341
≤ 2	32	2.69 (0.62)			
3-5	29	3.00 (1.70)			
6-10	24	2.68 (0.59)			
>10	13	2.38 (0.53)			
Relationship to patient			96	1.587	0.160
Spouse	11	3.56 (2.64)			
Children	14	2.34 (0.80)			
Sibling	23	2.73 (0.45)			
Another family member	27	2.74 (0.55)			
Parent	21	2.63 (0.64)			
Level of education			95	0.471	0.703
None	6	2.37 (0.57)			
Primary	3	2.73 (0.46)			
Secondary	37	2.66 (0.58)			
Tertiary	53	2.84 (1.34)			

The perceived stigma and its components were recoded into 3 categories: PDDS (<1 = low stigma; 2-4 = moderate stigma; 5-6 = high stigma); discrimination and devaluation (< 2.2 <1 = low stigma; 2.3-3.0 = moderate stigma; >3.1 = high stigma). These categories were cross-tabulated with socio-demographic variables to examine possible associations. These are shown in Table 11a, b and c. There was significant association between level of education and levels of stigma for the PDDS. Others did not show any significant associations.

Table 11a: PDDS disaggregated by socio-demographic characteristics of whole cohort of caregivers

Socio-demographic Variables	Low stigma n (%)	Moderate stigma n (%)	High stigma n (%)	Statistics
Level of Education				$\chi^2 = 13.759$ df=6
None	2 (20)	2 (3.1)	1 (9.1)	p=0.032
Primary	0 (0)	1 (1.6)	2 (18.2)	
Secondary	3 (30)	27 (42.2)	34 (53.1)	
Tertiary	5 (50)	34 (53.1)	6 (54.5)	
Relationship to patient				$\chi^2 = 10.396$ df=8
Spouse	1 (10)	7 (11.5)	3 (27.3)	p=0.238
Child	1 (10)	8 (13.1)	2 (18.2)	
Sibling	3 (30)	15 (24.6)	0 (0)	
Another member of	2 (20)	20 (32.8)	1 (9.1)	
family	3 (30)	11 (18.0)	5 (45.5)	
Parent				
Sole caregiver				$\chi^2 = 9.100$ df=2
Yes	3 (30)	17 (26.6)	8 (72.7)	p=0.011
No	7 (70)	47 (73.4)	3 (27.3)	
Gender				$\chi^2 = 3.844$ df=2
Male	7 (70)	25 (39.1)	6 (54.5)	p=0.146
Female	3 (30)	39 (60.9)	5 (45.5)	
Religion				$\chi^2 = 8.949$ df=4
Eckankar	0 (0)	0 (0)	1 (9.1)	p=0.062
Christianity	10 (100)	53 (82.8)	8 (72.7)	
Islam	0 (0)	11 (17.2)	2 (18.2)	

Table 11b: Discrimination disaggregated by socio-demographic characteristics of whole cohort of caregivers

Socio-demographic Variables	Low stigma n (%)	Moderate stigma n (%)	High stigma n (%)	Statistics
Level of Education				$\chi^2 = 5.326$ df=6
None	2 (15.4)	2 (3.8)	2 (6.9)	p=0.503
Primary	0 (0)	1 (1.9)	2 (6.9)	
Secondary	6 (46.2)	20 (38.5)	9 (31)	
Tertiary	5 (38.5)	29 (55.8)	16 (52.2)	
Relationship to patient				$\chi^2 = 6.198$ df=8
Spouse	2 (15.4)	7 (14)	2 (7.1)	p=0.625
Child	0 (0)	6 (12)	6 (21.4)	
Sibling	5 (38.5)	11 (22)	5 (17.9)	
Another member of	4 (30.8)	14 (28)	9 (32.1)	
family	2 (15.4)	12 (24)	6 (21.4)	
Parent				
Sole caregiver				$\chi^2 = 0.708$ df=2
Yes	4 (30.8)	19 (36.5)	8 (27.6)	p=0.702
No	9 (69.2)	33 (63.5)	21 (72.4)	
Gender				$\chi^2 = 0.088$ df=2
Male	6 (46.2)	22 (42.3)	13 (44.8)	p=0.957
Female	7 (53.8)	30 (57.7)	16 (55.2)	
Religion				$\chi^2 = 1.079$ df=4
Eckankar	0 (0)	1 (1.9)	1 (3.4)	p=0.888
Christianity	10 (76.9)	43 (82.7)	24 (82.8)	
Islam	3 (23.1)	8 (15.4)	4 (13.8)	

Table 11c: Devaluation disaggregated by socio-demographic characteristics of whole cohort of caregivers

Socio-demographic Variables	Low stigma n (%)	Moderate stigma n (%)	High stigma n (%)	Statistics
Level of Education				$\chi^2 = 4.900$ df=6
None	3 (11.1)	3 (6.3)	0 (0)	p=0.557
Primary	1 (3.7)	2 (4.2)	0 (0)	
Secondary	8 (29.6)	20 (41.7)	9 (37.5)	
Tertiary	15 (55.6)	23 (47.9)	15 (62.5)	
Relationship to patient				$\chi^2 = 11.683$ df=12
Spouse	2 (7.7)	6 (13)	3 (12.5)	p=0.471
Child	6 (23.1)	6 (13)	2 (8.3)	
Sibling	4 (15.4)	16 (34.6)	3 (12.5)	
Another member of family	7 (26.9)	11 (23.9)	9 (37.5)	
Parent	7 (26.9)	7 (15.2)	7 (29.2)	
Sole caregiver				$\chi^2 = 4.694$ df=2
Yes	8 (29.6)	12 (25)	12 (50)	p=0.096
No	19 (70.4)	36 (75)	12 (50)	
Gender				$\chi^2 = 1.512$ df=2
Male	9 (33.3)	21 (43.8)	12 (50)	p=0.470
Female	18 (66.7)	27 (56.3)	12 (50)	
Religion				$\chi^2 = 2.104$ df=4
Eckankar	0 (0)	1 (2.1)	1 (4.2)	p=0.717
Christianity	24 (88.9)	38 (79.2)	20 (83.3)	
Islam	3 (11.1)	9 (18.8)	3 (12.5)	

4.5.2 Comparison of expressed emotions between high and low perceived stigma among caregivers in the whole sample and between the urban and semi-urban samples

The total perceived stigma was dichotomised into two groups of high and low perceived stigma by using a cut-off point of 3 and above. The groups are compared along the dimensions of global expressed emotion and the components of emotional over-involvement and critical comments. This is shown in Table 12.

There was no significant difference found between those with high and low perceived stigma in terms of global expressed emotion and the components of emotional over-involvement and critical comments. Similar comparisons within the urban and semi-urban groups did not reveal any significant difference.

Table 12: comparison of high and low perceived stigma along dimensions of expressed emotion in the urban and semi-urban and whole samples

Variable	Low Stigma	High Stigma	Statistic	df	significance	95% CI
Cohort EE						
n (%)						
Present	23 (69.7)	10 (30.3)	0.273	1	0.065	
Absent	50 (74.6)	17 (25.4)				
mean (SD)						
EOI	20.12 (7.87)	21.37 (5.16)	0.558	98	0.360	-3.95 to 1.45
CC	15.25 (7.88)	14.70 (6.72)	0.215	98	0.274	-2.64 to 3.73
Urban EE						
n (%)						
Present	16 (66.7)	8 (33.3)	0.009	1	0.924	
Absent	17 (65.4)	9 (34.6)				
mean (SD)						
EOI	21.64 (7.29)	22.88 (4.88)	1.033	48	0.477	-4.74 to 2.25
CC	13.82 (7.08)	13.41 (7.14)	0.061	48	0.850	-3.92 to 4.74
Semi-urban EE						
n (%)						
Present	7 (77.8)	2 (22.2)	0.034	1	0.854	
Absent	33 (80.5)	8 (19.5)				
mean (SD)						
EOI	18.88 (8.19)	18.80 (4.78)	0.171	48	0.970	-4.03 to 4.18
CC	16.43 (8.39)	16.90 (5.61)	0.100	48	0.832	-5.09 to 4.12

4.6 Perceived Social Support in the urban, semi-urban and whole sample

The perceived social support among the caregivers was measured with perceived social support scale. This is shown in Table 13. The range of score is 0 to 24 with higher scores indicating high perceived social support. The range of scores from 0 to 8 is categorised as poor, 9 to 16 as fair and 17 to 24 as good perceived social support. In the component dimensions, 0 to 2, 3 to 5 and 6 to 8 represent poor, fair and good perceived support.

For the whole sample, the total perceived social support was fair with a mean of 14.01 (± 7.75), the perceived social support from family was fair with a mean of 5.34 (± 3.03), from friends was fair with a mean of 3.66 (± 3.07) and also fair among significant others with a mean of 5.01 (± 2.98). There was no significant difference in perceived social support between those in urban and semi-urban samples.

Table 13: perceived social support among the urban, semi-urban and whole sample population

	Total	**Urban**	**Semi-urban**	F	df	P	95% CI
PSSS total							
Mean	14.01 (7.75)	15.19 (7.23)	12.88 (8.13)	0.913	94	0.143	-0.719 to 5.427
95% CI	12.44-15.58	13.07-17.31	10.54-15-21				
Range	0-26	0-26	0-24				
Median	16.00	17.00	16.00				
IQR	12.75	12.00	15.00				
Significant others							
Mean	5.01 (2.98)	5.32 (2.76)	4.71 (3.18)	4.397	96	0.238	-0.479 to 1.908
95% CI	4.41-5.61	4.51-6.13	3.80-5.63				
Range	0-9	0-9	0-8				
Median	6.00	6.00	6.00				
IQR	5.75	4.00	6.50				
Family							
Mean	5.34 (3.03)	5.83 (2.75)	4.88 (3.24)	3.470	98	0.131	-0.279 to 2.119
95% CI	4.73-5.96	5.02-6.64	3.95-5.81				
Range	0-8	0-8	0-8				
Median	7.00	7.00	7.00				
IQR	5.75	4.00	6.50				
Friends							
Mean	3.66 (3.07)	4.04 (3.14)	3.29 (2.98)	0.607	95	0.182	-0.399 to 2.078
95% CI	3.03-4.28	3.12-4.96	2.43-4.14				
Range	0-10	0-10	0-8				
Median	3.00	5.00	3.00				
IQR	6.00	6.00	6.00				
Level of perceived Social support				0.901	2	0.637	
Poor	26 (26)	12 (46.2)	14 (53.8)				
Fair	50 (50)	24 (48.0)	26 (52.0)				
Good	24 (24)	14 (58.3)	10 (41.7)				

Chapter Five

Discussion

5.0 Introduction

The purpose of this thesis was to examine expressed emotions in semi-urban and urban families of persons with schizophrenia who are outpatients. This study attempts to extend insights into the experiences of informal caregivers in Nigeria by exploring the impact of burden of care and perceived stigma on EE among geographically diverse relatives of persons with schizophrenia. In order to achieve this, the thesis critically examined existing empirical evidence, the theoretical assumptions of family burden and EE models of families and schizophrenia. Research questions regarding the relationship between burden of care, perceived stigma, level of urbanization and expressed emotions were specified and these were tested by exploratory analysis of data from 100 caregivers of persons with schizophrenia living in semi-urban and urban settings in Nigeria.

This concluding chapter places the results of this study in the context of current research about people with schizophrenia and their families. The results of this thesis, both the critiques of EE, family burden, and models of families and schizophrenia and the results of the empirical tests are summarized. The methodological strengths and weaknesses of the research are discussed. Furthermore, the implications of the findings with respect to EE, perceived stigma and family burden in different geographical contexts are discussed and findings are compared with the results of published research. Implications for theory, research, policy and clinical practice with people with schizophrenia and their carers are discussed.

5.1 Thesis findings in context

Firstly, the socio-demographic characteristics of the participants are discussed in line with findings in research literature first. The study participants were all recruited from western part of Nigeria and appeared to be from a broad background providing a good basis for evaluating the impact of schizophrenia in the community.

The majority of carers were women which is in comparison with US report (Evercare and National Alliance for Caregiving (NAC), 2008; NAC and American Association of Retired Persons (AARP), 2009). This finding is consistent with the reports that majority (80%) people who provide informal caregiving are women (Schofield et al., 1998; Bedini and Phoenix, 2004). A review of literature showed that caregiving is often perceived as an exclusive purview of women because many of the demands of the sick people are often met by women in families (Walker and Pratt as cited in Lubkin and Larsen, 2006). In the event where the spouse is absent, daughters or daughters-in-law are mostly the people who have to undertake caregiving responsibilities. HPNY and NAC (2000) asserted that on average women spend 17 years of their lives rearing their children and another 18 years as caregivers to elderly parents, and people with mental illness if they have them as relations.

The finding of this study contrasts with Zahid and Ohaeri (2010) who found 66.1% of carers as men. The authors stated that their finding was a disproportionate one and might be due to the strict Arabian cultural rule that limited the role of women outside the home including bringing patients to hospital. Nonetheless, some authors have pointed out a

growing trend of male caregivers that is burgeoning (Schofield et al., 1997; Awad and Voruganti, 2008). In this study, about 4 out of ten carers were men similar to the 40% stated by Awad and Voruganti (2008). In a study of informal carers of Chinese people with schizophrenia in Hong Kong, proportion of men was higher (Chien, Norman and Thompson, 2004; Chien, Chan and Thompson, 2004). In another study conducted in New Zealand, 63% of carers were men (Collings, 2006). These authors in China and New Zealand contested that their finding illustrated the importance of not assuming that findings that are commonly made in some cultural contexts are relevant to others. This reason is plausible and so is the reason that there is growing trend in the proportion of male caregivers among persons with schizophrenia.

Majority of respondents were of Yoruba descent, were married and from monogamous setting. The average age of a caregiver was 42 years which is comparable to 46 years of age of caregivers providing care to an adult or a person with a mental illness according to HPNY and NAC 2000 report and not too dissimilar to the finding of Shibre et al. (2001) in Ethiopia where the mean age was 35.5 years and the finding of Philips et al. (2002) where the mean age was 49.5 years. About three in ten of the carers considered themselves the sole caregiver. Seven out of ten carers lived with the person they cared for and is consistent with that of Philips et al (2002) that 9 out of 10 respondents lived with the persons they cared for. The majority of carers were another member of the family caring for their relation with schizophrenia. This is consistent with the findings of NAC and AARP (2004) that reported 8 out of 10 caregivers being family members. Another finding from this study was that about 68% of carers were parents, children or siblings of

the patients and this is similar to findings of Zahid and Ohaeri (2010). This study also highlights the point made by Brodaty and Green (2002) that caregivers vary in their relationship to the care recipient (spouse, child, parent, another member of family); they may be the primary or secondary caregiver; they may live together with the care recipient or separately. The common thing is that caregiving for these respondents includes giving support and assistance to a family member who has special needs as posited by Walker, Pratt and Eddy in 1995.

Overall, respondents reported spending 35 hours a week caring for the person with schizophrenia; this is in comparison to 37 hours reported in the Australian carers report and the finding of 40.9 hours a week from Philips et al (2002) in China. It is far more than 22.5 hours in a recent European study (Flyckt et al., 2012). . In this study, seven out of ten carers lived together with the person with schizophrenia they cared for. Similarly, Flyckt and colleagues (2012) reported majority of carers lived with their ill relations. Those who did not stay in the same household with their sick relations were within a travelling time of about 7 minutes. Their upper limit of travelling time was 34 minutes and this is not different from the finding in 2012 by Flyckt and colleagues.

The impact of caring both affects paid and unpaid activities in this study. Majority of participants who participated in paid and unpaid activities in the last month were less able to fulfil their activities due to responsibilities of caring. This is similar to the findings of Zahid and Ohaeri (2010) wherein 60.4% of carers indicated that their caring role had affected their ability to pursue their activities regularly. A high proportion of carers in

this study stated that they provided a higher level of care when the person with schizophrenia was hospitalized. They also reported that caring for their relation with schizophrenia had at least moderate impact on their paid and unpaid activities. The respondents in Flyckt et al study reported that their productivity at work reduced by around 18% because of their caregiving situation. These findings resonate with the statement that while support for family and friends is a usual part of family and community life, informal care extends beyond the scope of this simple support (Biegel, Sales and Schulz, 1991). Pearlin and colleagues (1995) similarly characterized informal care as consisting of "activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves", which implies that informal care extends beyond normative activity. More certainly, the caregivers in this study could readily able to distinguish care-giving from ordinary family or friendship responsibilities. In line with research findings, they saw their care as 'extraordinary care' which is outside the boundaries of usual care though embedded in ordinary everyday relationships, and can come to dominate and restructure a relationship (Biegel, Sales and Schulz, 1991; Pearlin et al.,1995).

This study did not find significant difference in socio-demographic characteristics of carers in urban and semi-urban settings apart from ethnicity and whether or not the carer lived with the relation with schizophrenia.

Second, the thesis addressed the gaps in empirical evidence about the relationship between EE, burden of care and perceived stigma in different geographical contexts i.e.

semi-urban and urban settings in Nigeria. The research questions were: “does the level of burden of care among carers of patients with schizophrenia have impact on the level of expressed emotions?”, “does the magnitude of perceived stigma in carers of patients with schizophrenia affect their level of expressed emotions?” and “does the level of urbanization of carers of patients with schizophrenia affect their level of expressed emotions?” This thesis also sought to find out if expressed emotions differ between (1) carers with high burden of care and those with low burden of care; and (2) carers with high perceived stigma and those with low perceived stigma.

“Does the level of burden of care among carers of patients with schizophrenia have impact on the level of expressed emotions?” This study found that there was no significant association between the level of objective burden and global expressed emotion. This might be due to low statistical power and thus Type II error is possible. However, a significant medium positive correlation was found between objective burden and levels of critical comments. Objective burden helps to explain 15% of the variance in respondents’ scores on critical comments. Similarly, a significant measure of association was found between subjective burden and critical comments. This suggests that high levels of subjective and objective burden are associated with high levels of critical comments. The thesis findings confirm those of Scazufca and Kuipers (1996) that found relationship between criticism and subjective burden.

In other previous studies, there had been statistically significant and clinically important relationships between subjective burden and both EOI and criticism (Barrowclough and

Parle 19?; Bogren, 1996; Jackson et al., 1990; Scazufca and Kuipers, 1996; Smith et al., 1993). This study only found significant association between subjective burden and criticism. Some authors posited that reports of no association between EOI and subjective burden could be subject to Type II error because of small sample size (Bogren, 1996; Jackson et al., 1990). Another reason might be that this study looked at the relationships cross-sectionally. Nonetheless, these thesis findings provide further support to hypothesized relationship between components of EE and burden of care (subjective and objective).

The study asked if expressed emotion differed between those with high burden of care and those with low burden of care. It was found that the higher the level of financial burdens, the higher the level of disruption in family activity, the higher the level of disruption in family leisure, the higher the level of disruption in family interaction, the more affected the carers are in terms of physical and mental health, the higher the level of critical comments among carers. In other words, high family burden is associated with high expressed emotion and this is similar to the results of Scazufca and Kuipers (1996).

“Does the magnitude of perceived stigma in carers of patients with schizophrenia affect their level of expressed emotions?” There was no significant difference found between those with high and low perceived stigma in terms of global expressed emotion and the components of emotional over-involvement and critical comments. It should be noted that there is a small tendency for caregivers with low stigma to have low expressed emotion and for those caregivers with high perceived stigma to have high expressed

emotion given that the level of significance was close to being statistically significant. This is worthy of note because studies have found that relatives with low expressed emotions might tend to perceive stigma in ways that are less threatening thus have low perceived stigma while the caregivers who have high expressed emotion might perceive stigma more acutely and have high perceived stigma (Vaughn and Leff, 1981). This association is mediated by levels of anxiety of the caregiver to patient's illness according to these authors. Philips et al (2002) also reported similar finding. This study could not demonstrate this association probably because stable patients were used. Further studies need to put this into consideration. Nonetheless, it would appear likely from the foregoing that interventions that aims to reduce family members levels of expressed emotion might also target perceived stigma and vice versa.

"Does the level of urbanization of carers of patients with schizophrenia affect their level of expressed emotions?" The urban sample had significantly higher proportion of carers with high global expressed emotion (72.7%) than the semi-urban sample (27.3%). In this study, the odds of a carer who lives in an urban setting exhibiting high expressed emotion is 4.202 times higher than the odds of carer who lives in a semi-urban setting. The urban sample also had significantly higher proportion of caregivers with high emotional over-involvement (76.2%) compared with the semi-urban sample (23.8%). In fact, the odds of a carer who lives in an urban setting exhibiting emotional over-involvement is 4.237 times higher than the odds of a carer who lives in a semi-urban setting. Concerning critical comments the carers living in urban setting had 4.049 odds of exhibiting critical comments when compared with the odds of a carer who lives in semi-urban setting.

There were 76.5% carers with high critical comments in the urban sample compared to 23.5% of carers with high critical comments in the semi-urban sample.

Moreover, the prevalence of high EE in the whole sample in this study is 33%, EOI is 21% and CC is 17%. The prevalence of high EE in this study compares consistently with that in a London sample (47%) and the 23% in the Chandigarh sample. The high EE prevalence is comparable to 33% found in studies that examined clinical samples of informal carers (Lobban, Barrowclough and Jones, 2005; Wuerker, Haas and Bellack, 2001). The study by Collings in 2006 among New Zealand carers reported that 23.8% of carers had high EE. This author posited that the apparent lower prevalence of high EE in the sample was real and could be due to bias, other sampling characteristics or as pointed out by Roberts (2005) it could reflect differences in the expression of EE in the New Zealand population.

These thesis findings in addition to those above are important and interesting. On one hand, it is the first demonstration of urban-semi-urban difference in expressed emotion in an African country. This study aligns with other EE studies that provide specific level of analysis that is likely to advance our understanding of urban-semi-urban differences in EE and probably difference in outcomes. The findings thus are consistent with Leff and Warner's (2006) report that "a comparison across a wide variety of countries has shown that the prevalence of high EE households is greatest among the most industrialized and urbanized societies and least among rural agrarian societies." On the other hand, the findings confirm those from the DOSMed study in Chandigarh, India. In the Chandigarh

center's research, the prevalence of expressed emotion among carers of persons with schizophrenia in the city was 30% compared to the rate among carers in the rural areas which was 8%. This Indian study noted the contribution made by the generally low levels of EE to the good clinical outcome of persons with schizophrenia in that centre (Leff, 2008) and this might be generalizable though with caution to other countries including Nigeria.

This study found that caregivers' burden scores indicated moderate to severe level. This is similar to the finding of Gulseren and his colleagues (2010) among caregivers of outpatients living with schizophrenia in Turkey. Hou et al (2008) also found this among Taiwanese caregivers of persons with schizophrenia. Among the parameters of objective burden, financial burden had the highest score in this study. Studies had reported that caregivers burden increased as financial income became lower (Chien et al., 2007; Martens and Addington, 2001; Ohaeri, 2001; deSilva and deSilva, 2001). This is consistent with the finding of this study. About 8 out of 10 caregivers reported overall effect on mental health while 6 out 10 reported effect on overall physical health. Similarly, Flyckt et al (2011) reported that about half of the caregivers had at least moderate health problem. This finding is important when considered in the context of other findings. For instance caregivers' health has been identified as a significant predictor of caregiver depression (Lawton et al., 1992; Shah, Wadoo and Latoo, 2010). Poorer physical health among caregivers have been linked with increased risk of depression (Baumgarten et al., 1992) and longitudinal studies have demonstrated that caregivers are at greater risk than non-caregiving age-matched controls in developing mild hypertension (Shaw et al., 1997) and have increased risk for all-cause mortality

(Schulz et al., 1995). There was no significant difference when urban and semi-urban caregivers were compared in this study. Thus burden constitute the negative effects as well as actual or psychological costs of providing on-going caregiving support and this cuts across the dimensions of urban and semi-urban settings (Reinhard, 1994; Maurin and Boyd, 1990). Furthermore, in this study, high proportion of caregivers had burden that had to do with family routine disruption and family interaction disruption. This is similar to what Karanci (1995) and Chandrashekar (2008) found.

In this study, the significant predictors of objective burden in the carers were living with a person with schizophrenia, social support, number of admissions, and discrimination. The carer who lives with a relation with schizophrenia has the odds of 4.386 times to have objective burden compared with a carer who did not live with a relation with schizophrenia. The higher the number of admissions in hospital of a person with schizophrenia, the odds of this carer having objective burden is 4.219 times the odds of a carer of a person with schizophrenia who had no admissions. When a carer has perceived discrimination the odds of this person having objective burden is 4.082 times the odds of a carer who did not have perceived discrimination. A carer without perceived social support has 3.311 odds of having objective burden than a carer of a person with schizophrenia who has perceived social support.

The finding that living with relations with schizophrenia predicted burden has been found in other studies (Tessler and Gamache, 1994; Pickett, Greenley and Greenberg, 1995; Jones, Roth and Jones, 1995; Baronet, 1999). This is of significance because studies have

indicated that many family caregivers reported not having the knowledge and skills necessary to take on the responsibilities of caregiving for their relatives (Chan, 2011). In addition, they have inadequate help and support, face daily stressors of unpredictable and bizarre behaviours of their relative mixed within a tapestry of external stressors of stigma, emotional frustration and family conflicts in the caring process. The closer a carer is to a person with schizophrenia in terms of residence, the more likely and more frequently this carer encounters these variables compared with a carer who resides away from the relation with schizophrenia.

The predictor of caregiver burden in family caregivers in an Asian study was social support (Chien et al., 2007). Magliano and colleagues (2003) demonstrated in their study that relatives of persons with schizophrenia who had a supportive network reported lower levels of burden. Similar findings were demonstrated in other studies (Caudle, 1993; Dyck, Short and Vitaliano, 1999; Saunder, 1999; McDonell et al., 2003; Chen and Greeberg, 2004; Chien, Chan and Morrissey, 2007). The finding of these several authors is consistent with that of this study as pointed out above in the significant predictors of burden. Social support has profound effects on caregiver outcomes (Shah, Wadoo and Latoo, 2010). Social support and caregiver burden have been found to mediate depression in caregivers (Clyburn et al., 2000). More social support corresponds to less depressive symptoms (Baumgarten et al., 1992) and lower perceived burden (Gallant and Connel, 1997). Caregiver burden was thus more likely to be high when caregivers had low levels of social support. The literature review in this study noted that evidences from different countries on family caregivers of persons with schizophrenia generally support that there

is inadequate help and support to the family caregivers (Chan et al., 2009; Chan, 2011). Thus as suggested by Chan (2011), a useful strategy to alleviate the burden of caregivers of persons with schizophrenia might be to strengthen their social network. However, it should be noted that Rose, Mallinson and Gerson (2006) mentioned that caregivers burden was not alleviated by the presence of extended family because their support was not always available and family members disagreed about what mental illness is and how it should be treated. This underlies that fact that it is perceived social support that predicts burden. Chiou et al (2009) posited that perceived social support was better at predicting caregiver burden than received social support. This should be factored into strategies to alleviate caregivers' burden. There was no significant difference found between the caregivers who lived in urban and semi-urban locale on all the dimensions of perceived social support.

The cohort of caregivers perceived that social support from family, friends and significant others was averagely fair in this study.

In the review of literature, it was found that age of carers has been positively associated with levels of burden in many studies (Cook et al., 1994; Jones, Roth and Jones, 1995; Pickett et al., 1997; McDonell et al., 2003; Chien et al., 2007; Chan et al., 2009) than studies where caregivers with younger age experienced higher levels of family burden (Magana et al., 2007). This relationship was not found in this study. Lauber and colleagues (2003) posited that level of burden might change over time as the nature of the relationship with the patient changes with the illness trajectory. Thus a cross-sectional study such as this might not capture this relationship. A longitudinal study might therefore be relevant in resolving this issue. A critical review of literature by Baronet

(1999) showed that the association between caregivers' age and overall burden yielded mixed findings. This author suggested that the intensity of crisis period for the mentally ill relation when the data were collected could be a confounding factor. He posited that one study that did not find any relationship between caregivers' age and overall burden (Reinhard, 1994) involved participant caregivers caring for an ill relative in a stable condition. This was the situation in this study where outpatients with schizophrenia were used. The other studies Baronet (1999) reviewed involved participant caregivers caring for an ill relative recently admitted to a psychiatric setting (Horwitz and Reinhard, 1995; Stueve et al., 1997).

Baronet explained further that possibly “caregivers' age is negatively related to overall burden when the ill relative is in a crisis condition (exacerbation of symptoms), but that age is not related to overall burden when the ill relative is in a stable condition because older caregivers may have more experience in dealing with symptomatic behaviors.” Another possibility for the mixed finding could be in the dimensions of burden studied (Baronet, 1999). It was found that younger caregivers were more burdened by the management of disruptive behaviors of the ill relative whereas older caregivers were more burdened by feelings of ongoing responsibility for the ill child.

The mixed findings including no association raised some issues. First, it could be that caregivers of various ages could be burdened by different aspects of caregiving. Second, it could be that cross-sectional studies could find no association when ill persons are in stable condition. Third, the level of burden might change over time. Further longitudinal

studies are therefore needed to resolve these issues. In addition, these further studies should control for the amount of experience in caregiving.

Consistent with this study's finding of relationship between number of hospitalizations and burden are findings of several authors (Gibbons et al., 1984; Raj, Kulhara, and Avasthi, 1991; Pickett et al., 1993; Biegel et al., 1994; Cook et al., 1994; Salleh, 1994; Soloman and Draine, 1995; Pickett, Greenley and Greenberg, 1995; Provencher and Meuser, 1997; Dyck, Short, and Vitaliano, 1999; Martens and Addington, 2001; McDonell et al., 2003; Yeh et al., 2008; Aydin et al., 2009). It is important to note that not all researchers consistently find this link (Lowyck et al., 2001). Some authors surprisingly did not find burden related to number of hospitalizations (Barrowclough and Tarrier, 2003; Rose, Mallinson and Gerson, 2006). These authors posited that it might be possible that families view mental illness from a more global perspective, with their preoccupation centred on the future rather than the past or that families feel more bothered by negative symptoms than positive symptoms of mental illness that got patients admitted several times. Nonetheless Gulseren et al (1999a) suggested that repeated hospitalizations in the context of schizophrenia increases the burden of caregivers. There is need to take note of this and other factors because patients with schizophrenia are increasingly being treated at outpatient clinics and are cared for by family members. Thus intervention studies to reduce the burden of care need to consider this factor among others.

It is of note that across studies, burden of care has been found associated with stigma related to mental illness, and that this stigma can pose threats to carers which may result in prejudice and discrimination (Chan, 2011). The finding in this study that perceived discrimination predicted objective burden confirms further this assertion. It would be of help to help family caregivers cope with stigma of mental illness through cognitive restructuring but more particularly through community education and through a willingness among individuals to challenge the stigma of mental illness.

According to Chan (2011) it appears that the major effects of caregiving such as financial difficulties, disruption of family routine and interaction as well as leisure are common across cultures and this study adds to the literature in this regard. Negative perceived social support, high number of admissions in relations with schizophrenia, perceived discrimination, and living with relations with schizophrenia impact negatively on burden of care. In other words, the problem of family burden of caring for persons with schizophrenia is a common challenge in both developed and developing countries. However, this study, while comparing urban and semi-urban settings, noted that in addition to overall objective burden, other parameters of objective burden namely financial burden, disruptions in family leisure and family interactions were significantly worse in urban settings. This underlies the significance of level of urbanization in the determination of burden of care among carers of persons with schizophrenia. This study's finding is in contrast with earlier findings of Martyns-Yellowe (1992) in the Southern region of Nigeria. This author reported that rural families experienced more burden than urban families and this was only in respect of financial burden. The author explained that

the finding was more likely due to transportation costs to the city where mental health clinic was and then the difference in socioeconomic status of caregivers in rural and urban setting. There is difference between this study and that of Martyns-Yellowe: the comparison was not between semi-urban and urban settings.

Perceived stigma was moderately high. So were devaluation and discrimination scores among the whole sample. About 9 out of ten caregivers had moderate to high perceived stigma in this study, while about 8 out of 10 had moderate to high perceived discrimination and about 7 out of 10 had perceived devaluation. Majority (75.3 %) of the caregivers had moderately high perceived stigma, (52%) moderately high discrimination and (48%) moderately high devaluation stigma. On one hand, these findings were consistent with that of Shibre and colleagues (2001) among family members of individuals with schizophrenia in rural Ethiopia. They found that 75% of respondents had perceived stigma. One the other hand, these findings were not consistent with those of Struening and colleagues (2001) where about 5 out of 10 caregivers had perceived stigma and that of Angermeyer and colleague (1997) where 3 out of 10 caregivers surveyed had discrimination.

Shibre and colleagues (2001) found that there were few differences between socio-demographic groups in stigma just similar to the findings in this study. Hinshaw (2005) reported that in conditions such as schizophrenia, parents and siblings are more likely to have perceived stigma. This could be as a result of parents and siblings being unfairly blamed by their immediate community (Sankar et al. 2006; Burnes et al 2008) or that

they blame themselves with consequent high levels of guilt (Murray 1976). This study found in addition to parents and siblings having perceived stigma, another member of the family also had at least moderate perceived stigma. This is also true of discrimination and devaluation.

Another interesting finding was that high perceived stigma was commonest among the spouses, followed by parents and children. This could be due to the fact that many of these caregivers are sole caregivers to the persons with schizophrenia. It is also interesting that a higher proportion of the sole caregivers had high perceived stigma. Higher proportion of the caregivers was women, and a higher proportion of women had at least moderate to high perceived stigma, discrimination and devaluation. This resonates with the literature that showed that most caregivers were females and experienced perceived stigma (Thara and Srinivasan, 2000; Shibre et al., 2001).

This study found that caregivers with higher education had the more perceived stigma than those with lower levels of education. This is support of the findings from several authors (Angermeyer et al., 1987; Phelan et al., 1998; Philip et al., 2002). These authors suggested that such family members might feel they had more to lose. In addition, those with higher education could recognise more the burden resulting from lack of support by the State or health insurance as a core form of structural discrimination of relaties of persons with mental health problems; they may also be more aware of the stigma resulting from negative media coverage; and their cognitive appraisal of the imbalances and injustices inherent in social structures, political decisions and legal regulations. These

might interact with their feelings of helplessness and result in perceived stigma more than those with lower levels of education.

In contrast to the finding of Shibre and colleagues that older caregiver were more likely to have perceived stigma, this study did not find any such difference. Other studies reported that younger age group was associated with higher stigma (Thara and Srinivasan, 2000). The difference in these findings to those of this study could be due to differences in culture, setting and other factors.

This study is important in that it is among the few studies to highlight the importance of stigma among caregivers of persons with schizophrenia in sub-Saharan Africa. In the developed countries, there were mixed findings about the amount of stigma experienced by participants. Some studies found low level of stigma (Asai, 1983) while others found high levels of stigma (Ryder, Bean and Dion, 2000; Kadri et al., 2004: all cited in Rooney, Wright and O'Neil, 2006). Much work needs to be done in sub-Saharan region to confirm the findings of this study on stigma.

This study also found that there was significance difference between the urban and semi-urban caregivers along the discrimination dimension. The odds of a caregiver living in urban having moderate discrimination is 5.5 times the odds of caregiver living in semi-urban while the odds of caregivers living in urban having high discrimination is 7.79 times the odds of caregiver living in semi-urban. This may be due to less favourable family and social support and less traditional society in town. In line with Philips and colleagues (2002), this might probably be related to higher level of external supervision

of the behaviour person's with schizophrenia in the more densely population urban district or lack of close (supportive) ties in urban settings where neighbours are frequently strangers and would see mental illness as a taboo.

With regards to perceived stigma, there was almost a significant difference found between carers who lived in urban and semi-urban areas. The odds of caregivers living in urban having moderate stigma is 2.3 times the odds of caregiver living in semi-urban while the odds of caregivers living in urban having high stigma is 10.5 times the odds of caregiver living in semi-urban. This study literature revealed that in rural dwellings informal carers might be blamed unfairly and thus stigmatised more than in urban dwelling because people in urban settings believed in the biopsychosocial cause of mental illness such as schizophrenia while in rural dwelling they believed the cause was supernatural (Adewuya and Makanjuola, 2008). However, in contrast to the extrapolation of these authors, stigma is more in the urban setting in line with explanation provided above by Philips and colleagues (2002). This is also consistent with the finding of Shibre and colleagues (2001) where urban residents were more likely to perceive stigma as a major problem.

It should be of note that perceived stigma can have serious disabling consequences due to the tendency by affected individuals to take, sometimes, extra-ordinary measures to conceal their attribute (Scambler, 2004; Scambler and Hopkins, 1986). Typically, the consequences of these efforts to avoid disclosure include isolation and loss of social and economic opportunities (Leary et al., 1998) apart from making deliberate and seemingly

irrational decision not to seek help (Sadavoy et al., 2004). In general, stigma is not related much to socio-cultural factors and thus is shared commonly among nearly all community members (Alem et al., 1999). Stigma among relations of persons with schizophrenia has social implications. It could be a major obstacle to recovery and can limit opportunities of work and social functioning of family members.

5.2 Strengths and limitations of the study:

This study has particular strengths in relation to the practice of research. First, this study drew on critical realist perspectives that explored EE and family burden paradigms and making them compatible with the stress-diathesis model where neither the family nor the persons with schizophrenia are the problems or outcome in order for the reciprocal effects between carers and persons with schizophrenia to be recognized. Second, this study used the process of consulting with patients about the identification of relevant carer and this is consistent with the need for participants to have appropriate autonomy in the research process and to be truly giving truly informed consent (Reiser, 1993; Peterson, 1998; Thornicroft and Tansella, 1999). Third, the study recruited by explicit means a diverse group of informal carers who had been identified by index out-patients and the response rate was high. Fourth, the socio-demographic characteristics of the carers were fully described so that the study would have utility for policy making and service planning. Fifth, this is the only study that looked at possible differences in EE along the urban-semi-urban dimensions in Africa and in Nigeria, and its external validity is likely to be high within the Nigerian context. The external validity outside Nigeria may

be more limited even though it would contribute to emerging literature of cross-national findings.

The study is limited as well. First, it could be argued that singling out one carer for each patient might be unnatural because this introduced constraint on what will clearly be a social network around the index patient. Nonetheless, studies have shown that caregiver experiences do not vary significantly between key and other carers for people with schizophrenia (Magliano et al., 1999; Collings, 2006). Second, this study was cross-sectional and could not investigate direction of effect. Thus all observations of associations have been cautiously reported as cross-sectional associations. Third, the use of some instruments which had not been formally validated in the Nigerian population such as the Family Questionnaire (FQ), the Perceived Devaluation and Discrimination Scale (PDD) and Multidimensional Scale of Perceived Social Support (MSPSS), means that findings based on these measure might be of lesser validity than would otherwise be the case. However, it is rational to make use of measures based on compromise between what is available, the right psychometric properties, suitable length of questionnaire for interviewees, ease of understanding and suitability for populations with low literacy levels. Furthermore, the use of such novel instruments could actually add to current knowledge of these instruments and provide some evidence that these can be used with confidence. Fourth, the sample size of 100 for EE analysis is a potential limitation. However, it has been argued by authors that if a difference cannot be detected in a moderately sized sample, then it may not have utility in the real world or be clinically meaningful. Furthermore, 100 is not an especially small sample in this area of research.

5.3 Implications for theory, clinical practice, policy and research

The findings in this study when integrated with existing research have broad implications for theory, clinical practice, policy and research. First, the importance of informal caregivers in clinical and social systems of care for people with schizophrenia has been highlighted further in this study. This study highlights the usefulness of unifying the expressed emotional paradigm and family burden paradigm with stress-diathesis model. This unifying paradigm highlights the reciprocal effects between caregivers and their relations with schizophrenia within the context of geographical variation. This study has highlighted the possible differential impact of rural and urban settings on expressed emotion, family burden, courtesy stigma and social support which are important in defining positive or negative experiences of families with a member with schizophrenia. The caring experience could be seen as both context dependent and context specific.

Second, the study underlies the importance of caregivers when given adequate support and intervention as useful resources, co-workers and co-clients with health professionals interested in the care of persons with schizophrenia. This typology of informal carers has the potential to support the development of a useful approach to care of persons with schizophrenia from a policy and service provision perspective.

Third, the contrast between key findings in this study and other studies in the literature do provide clinical wisdom such that individual practitioners in clinical situation would adopt a thoughtful stance towards the carers they meet.

Fourth, the findings from this study identify the need for psycho-educational interventions for carers of people with schizophrenia. There has been poor uptake in mental health services despite evidence for their efficacy in improving the course of the illness among people with schizophrenia. The results of this study suggest that informal caregivers have peculiar needs that require attention. Financial support through insurance schemes and other similar schemes would probably improve their quality of life as well as that of the people with schizophrenia they care for. Improvement of the mental and physical health might ameliorate some effects of EE on persons with schizophrenia. The suggestion in this study that there might be geographical variation in some parameters of perceived stigma, family burden and expressed emotion deserves consideration in mental health policy and services for persons with schizophrenia and their informal caregivers.

Fifth, the findings that others caregivers, apart from parents and sole caregivers, have similar problems suggest that all carers should be considered in all interventions and support initiatives. Clinicians should not focus only on index patient with schizophrenia but also consider all caregivers as partners with health services truly working together towards shared goals. Positioning the patient and carer together at the center of clinical focus is considered to be the gold standard (Collings, 2006).

Sixth, the key to meaningful attention to informal carers of persons with schizophrenia is the amendment of mental health policy in response to local data given the evidence in this study that supports other previous studies.

Seventh, within the discourse of this thesis, a number of areas for further research have been indicated. Given that informal caregiving is a dynamic process, it is hoped that more longitudinal studies are conducted to better understand the complexities of informal carer experience over time and in different locales.

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APPENDIX I

Research Serial Number: _____Hospital Number: _____
Age in years: _____
Gender Male □ Female □
Marital status : _____
Ethnicity (Tribe): _____
Family type : Monogamous □ Polygamous □
Perceived level of social support from others or relatives …….(poor) / (Fair) / (Good)
Religion: _____ Your occupation: _____
Your level of education Primary(1-6) □ Secondary (JSS1-SSS3) □ Tertiary (College of Education/Polytechnic/University) □ None □
For relation with mental illness: Age of onset of illness in relation_____ Number of hospital admissions _____ Duration of illness from the 1st hospital admission _____

APPENDIX II

Family Questionnaire

	Never/very rarely	Rarely	Often	Very often
1. I tend to neglect myself because of him/her				
2. I have to keep asking him/her to do things				
3. I often think about what is to become of him/her				
4. He/she irritates				
5. I keep thinking about the reasons for his/her illness				
6. I have to try not to criticize him/her				
7. I can't sleep because of him/her				
8. It's hard for us to agree on things				
9. When something about him/her bothers me, I keep it to myself				
10. He/she does not appreciate what Ido for him/her				
11. I regard my own needs as less important				
12. He/she sometimes gets on my nerves				
13. I'm very worried about him/her				
14. He/she does some things out of spite				
15. I thought I would become ill myself				
16. When he/she constantly wants something from me, it annoys me				
17. He/she is an important part of my life				
18. I have to insist that he/she behaves differently				
19. I have given up important things in order to be able to help him/her				
20. I'm often angry with him/her				

APPENDIX III

Perceived Devaluation-Discrimination Scale

	Don't Know	Strongly agree	agree	Neither agree nor disagree	disagree	Strongly disagree
1. Most people would willingly accept a former mental patient as a close friend						
2. Most people believe that a person who has been in a mental hospital is just as intelligent as the average person						
3. Most people believe that a former mental patient is just as trustworthy as the average citizen						
4. Most people would accept a fully recovered former mental patient as a teacher of young children in a public school						
5. Most people feel that entering a mental hospital is a sign of personal failure (R)						
6. Most people would not hire a former mental patient to take care of their children, even if he or she had been well for some time (R)						
7. Most people think less of a person who has been in a mental hospital (R)						
8. Most employers will hire a former mental patient if he or she is qualified for the job						
9. Most employers will pass over the application of a former mental patient in favor of another applicant (R)						
10. Most people in my community would treat a former mental patient just as they would treat anyone						
11. Most young women would be reluctant to date a man who has been hospitalized for a serious mental disorder (R)						
12. Once they know a person was in a mental hospital, most people will take his opinions less seriously (R)						

APPENDIX IV

Family Burden Interview

	No burden	Moderate burden	Severe burden
A. Financial burden overall			
1. Loss of patient's income: (Has he lost his job? Stopped doing the work which he was doing before? To what extent does it affect the family income?)			
2. Loss of income of any other member of the family due to patient's illness: (Has anybody stopped working in order to stay at home, lost pay, lost a job? To what extent are the family finances affected?)			
3. Expenditure incurred due to patient's illness and treatment: (Has he spent or lost money irrationally due to his illness? How much has this affected the family finances? How much has been spent on treatment, medicines, transport, accommodation away from home and so on? How much has been spent on other treatments such as temples and native healers? How has this affected family finances?)			
4. Expenditure incurred due to extra arrangements: (For instance, any other relative coming to stay with the patient; appointing a nurse or servant; boarding out children. How have these affected the family finances?)			
5. Loans taken or savings spent: (How large a loan? How do they plan to pay it back? How much does it affect the family? Did they spend from savings? Were these used up? How much is the family affected?)			
6. Any other planned activity put off because of the financial pressure of the patient's illness: (For instance, postponing a marriage, a journey or a religious rite. How far is the family affected?)			
B. Disruption of routine/family activities overall			
1. Patient not going to work, school, college, etc: How inconvenient is this for the family?			
2. Patient not helping in the household work: How much does this affect the family?			
3. Disruption of activities of other members of the family: (Has someone to spend time looking after the patient, thus abandoning another routine activity? How inconvenient is this?)			
4. Patient's behaviour disrupting activities: (Patient insisting on someone being with him, not allowing that person to go out, etc? Patient becoming violent, breaking things, not sleeping and not allowing others to sleep? How much does it affect the family?)			
5. Neglect of the rest of the family due to patient's illness: (Is any other member missing school, meals, etc? How serious is this?)			

APPENDIX V

Family Burden Interview

	No burden	Moderate burden	Severe burden
C. Disruption of family leisure overall			
1. Stopping of normal recreational activities: (Completely, partially, not at all? How do the family members react?)			
2. Patient's illness using up another person's holiday and leisure time: (How is this person affected by it?)			
3. Patient's lack of attention to other members of the family, such as children, and its effect on them.			
4. Has any other leisure activity had to be abandoned owing to the patient's illness or incapacity e.g. a pleasure trip or family gathering? How do the family members feel about it?			
D. Disruption of family interaction overall			
1. Any ill effect on the general atmosphere in the house: (Has it become dull, quiet? Are there a lot of misunderstandings, etc? How do the family members view this?)			
2. Do other members get into arguments over this (for instance over how the patient should be treated, who should do the work, who is to blame, etc)? How are they affected?			
3. Have relatives and neighbours stopped visiting the family or reduced the frequency of their visits because of the patient's behaviour or the stigma attached to his illness? How does the family feel about this?			
4. Has the family become secluded? Does it avoid mixing with others because of shame or fear of being misunderstood? How do the members feel about this?			
5. Has the patient's illness had any other effect on relationships within the family or between the family and neighbours or relatives e.g. separation of spouses, quarrels between two families, property feuds, police intervention, embarrassment for family members, etc? How does the family feel about it?			
E. Effect on physical health of others overall			
1. Have any other members of the family suffered physical ill health, injuries, etc due to the patient's behaviour? How has this affected them?			
2. Has there been any other adverse effect on health (e.g. someone losing weight or an existing illness being exacerbated)? How severe is it?			
F. Effect on mental health of others overall			
1. Has any other family member sought help for psychological illness brought on by the patient's behaviour (for instance by the patient's suicide bid, or his disobedience, or worry about his future)? How severe is this?			
2. Has any other member of the family lost sleep, become depressed or weepy, expressed suicidal wishes, become excessively irritable, etc? How severely?			
Finally, is there any other burden on the family about which we have not asked you? If so, what is it? How badly does it affect you?			
How much would you say you have suffered owing to the patient's illness - severely, a little or not at all?			
1. Are you the sole caregiver for the person with schizophrenia whom you care for? Yes □ No □			
2. What is your relationship to the person with schizophrenia whom you care for ?			

Husband/wife/partner □ Child □ Sibling (brother or sister) □
Another member of the family □
Friend/neighbour □ Other (please specify)…….

3. How long have you been caring for the person with schizophrenia specifically in relation to their schizophrenia? …….. Years and months

4. Do you live with the person with schizophrenia whom you care for ?

Yes □ No □
Sometimes (please specify e.g. half the week; whenever they come home)
…….

a) If you answered 'no' or sometimes, what are the living arrangements of the person you care for ?

They live alone □ ; They live with other family members □
Others (please specify) ……..

b) If no or sometimes, approximately how much time per week do you spend travelling to where s/he lives (including public transport, car travel etc.)?

…… hours

5. How much time per week on average do you spend directly caring for the person with schizophrenia (caring includes housework, meals, organising appointments, helping with day-to-day living such as dealing with the bank on their behalf etc.)

…….hours for ……days a week

6. When the person you care for has been in hospital, how would you rate any change in the level of caring provided by you?

a) the level of care I provide is less than usual
b) the level of care I provide is the same as usual
c) the level of care I provide is more than usual
d) the person I care for has never been hospitalised

7.Does the person you care for have any long term physical illnesses that add to the time you spend caring for them

Yes □ No □
if yes, can you please outline the conditions below:

8. In the past month do you have any paid employment? Yes □ No □

9. In the past month, did you have to take any time off paid work because of caring for someone with schizophrenia?

Yes □ No □

10. In the past month do you have any unpaid job/leisure activities you do? Yes □ No □

11. In the past month, did you have to take any time off unpaid work/activities because of caring for someone with schizophrenia?

Yes □ No □

12. On these days, to what extent did caring for a person with schizophrenia affect your unpaid work/activities on a scale of 0 to 10

APPENDIX VI

Multidimensional Scale of Perceived Social Support (MSPSS)

	Agree	Neutral	Disagree	Do not know
1. There is a special person who is around when I am in need				
2. There is a special person with whom I can share my joys and sorrows				
3. my family really tries to help me				
4. I get the emotional help and support I need from my family				
5. I have a special person who is a real source of comfort to me				
6. my friends really try to help me				
7. I can count on my friends when things go wrong				
8. I can talk about my problems with my family				
9. I have friends with whom i can share my joys and sorrows				
10. There is a special person in my life who cares about my feelings				
11. My family is willing to help me make decisions				
12. I can talk about my problems with my friends				